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A Descriptive Study of Military Family Needs Following a Polytraumatic Injury

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A Descriptive Study of Military Family Needs Following a Polytraumatic Injury

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Abstract

A DESCRIPTIVE STUDY OF MILITARY FAMILY NEEDS
FOLLOWING A POLYTRAUMA

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A dissertation submitted in partial fulfillment of the requirements for the degree of
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Family members of service personnel with polytraumatic injuries face a wide range of challenges. Research has shown that family member adaptation and adjustment to the caregiver role has a significant impact on the well-being of the person with the injuries. The Veterans Health Administration is rapidly developing services to meet the needs of severely injured service personnel and their family members. The purpose of the present study was to test the feasibility of a method of assessment to identify the needs of individual family members of service personnel and veterans receiving inpatient rehabilitation services at the Polytrauma Rehabilitation Center (PRC) located within the Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia. Family member needs and emotional distress levels were quantitatively assessed. Qualitative data was collected with the intent of gaining a better understanding of the needs of families of individuals with severe injury from within a military cultural context. Results of this study suggest emotional distress levels of family members of persons receiving treatment on the PRC are not clinically significant. Study participants report overwhelming satisfaction with the program of care offered to patients and family members on the PRC. Furthermore, results of this study suggest that family members

benefited from participating in the study. A strength-based family care pathway that utilizes an individual assessment of family needs is proposed and recommended for use with family members of individuals enrolled in the Veterans Health Administration polytrauma network services.

Chapter I

Introduction

The Department of Veterans Affairs (DVA) and the Department of Defense (DoD) report they are in a partnership to meet the needs of their "newest" veterans – the men and women who served in Operation Iraqi Freedom and Operation Enduring Freedom (OIF/OEF; DVA, 2005). With the number of seriously injured troops returning from OIF/OEF numbering over 20,000, one of the goals of the VA is to ensure that every seriously injured or ill service member returning from combat receives priority consideration and world-class service (DoD, 2006; DVA, 2006). In an attempt to meet this goal, the VA has established four primary polytrauma rehabilitation centers and 21 Level II rehabilitation units in the United States to provide integrated care for troops suffering severe injuries and the multiple complications that can follow (DVA, 2006). The idea behind this plan is to provide each severely injured service member and his or her family with a seamless transition from the combat zone to a VA outpatient Level II rehabilitation facility closest to his or her hometown. Family members of wounded service personnel are encouraged to be actively involved in the care, treatment and disposition planning of the patient.

Military service members and their families make up a unique subculture within the larger society it serves. It is a closed community with unique customs, cultural norms, diverse membership, and defining rank structure. It typically includes service members and their dependent family members (spouses and children). However, non-dependent parents and siblings of military personnel may feel a strong relationship with this subculture. Military deployments and duty-related separations are well-

documented as significant sources of stress for military families, but still considered a normative stress from within the military cultural context (Boss, 2002; Wiens & Boss, 2006).

When a service member is deployed to a combat zone, universal normative daily family stressors are accompanied by catastrophic stress associated with anticipatory fear of death or injury of the service member (Wright, Burrell, Schroeder, & Thomas, 2006). The stress and stress reactions associated with separations and anticipatory fears, exacerbated by real-time exposure to the hostile daily living environment of the service member that is communicated via email, phone, and television, may have negative mental and physical health consequences for those left behind (Dirkzwager, Bramsen, Ader, & Van der Ploeg, 2005; Figley, 1993, 2005; Motta, Newman, Lombardo, & Silverman, 2004; Wright et al., 2006).

However, not all stress and change produce negative outcomes. Current research typically measures stress and burden, leaving family members little to no opportunity to provide responses in relation to positive experiences, resiliency, or "uplifts as opposed to burdens" (Duff, 2006, p.12). Separation prior to injury might actually have positive implications for family members. A deployment to a combat zone may also provide a unique opportunity for families to grow, become stronger, and develop adaptive coping and management skills that will serve them in future normative and catastrophic stress situations (Wiens & Boss, 2006).

When a service member is injured, the anticipatory fear family members may be experiencing turns to shock and families find themselves in an acute crisis situation after they learn their loved one has been injured, but before they learn the extent of the injuries

and initial diagnosis. This crisis is exacerbated by the fact that the next of kin cannot drive down to the local hospital to see their loved-one, but must wait until he or she is evacuated from the combat zone. The evacuation pathway and process depends on the patient's injuries, availability and safety of medical evacuation transportation, and priority of movement with respect to other injured patients. Delivering information about the specific nature of the injury back to the family member from a combat zone is challenging due to the fact that the patient is moved as quickly as possible from the battlefield and through various levels of treatment facilities in several different countries, depending on the severity of the patient's injury. The acute crisis families experience when they receive "the phone call" that their service member was injured marks the beginning of a challenging and life-long journey that may produce despair, a return to homeostasis or growth.

Traumatic brain injury (TBI) is the signature injury of the Iraq War. The Department of Defense (2006) reports that injury from explosions is the most common cause of evacuation from Iraq. These "blast" injuries, typically caused by road-side bombs or improvised explosive devices (IEDs), have concussive, projectile, and fire/burning components (DePalma, Burris, Champion, & Hodgson, 2005). The concussion of the explosion and the spewing of shrapnel cause complex, multi-system injuries to the service member. These polytraumatic injuries include, but are not limited to, closed and/or penetrating traumatic brain injury (TBI), bone fractures, loss of limbs, spinal cord injury, burns, loss of vision and internal injuries. Patients who are treated at the Polytrauma Rehabilitation Center in Richmond, Virginia have a polytraumatic injury that includes a TBI along with one or more other injuries.

These injuries are treated by professionals from multiple disciplines, with family members participating as an important member of the treatment team. Family members play a vital role in the recovery of a person with a TBI (Lezak, 1986; Rosenthal & Young, 1988). Over the past two decades, the rehabilitation literature has provided information on family members' reactions to injury, common challenges faced by family members, risk factors for poor adjustment, and changes in family functioning post-injury (Kreutzer, Kolakowsky-Hayner, Demm, & Mead, 2002). The identification of needs and need-based interventions with family members plays an important role in reducing the potential negative health consequences and enhancing growth outcomes for family members who care for those who have served (Marks & Daggett, 2006; Rosenthal & Young, 1988).

A contextual model of family stress management (Boss, 2002) addresses the unique internal and external cultural context of military families coping with a traumatic injury, while encompassing the traditional elements of family stress theory (Hill, 1949). Theories and programs that emphasize a strength-based and resiliency approach are used by the military when preparing families for the emotional cycle of their loved-one's deployment and the ambiguity surrounding the deployment (Wiens & Boss, 2006). These same theories are also applied to military family members who are adjusting to life with an ambiguous future surrounding the outcome of the injury. These theoretical models, together with the rehabilitation literature, provide insight into the complex context surrounding the families of severely injured military personnel.

Gaining a direct understanding of military families through an understanding of their daily living environment may provide valuable and timely data that can immediately

inform the rapidly developing polytrauma programs within the Veterans Health Administration. Thus, the purpose of this study was to test the feasibility of a method of assessment to identify the needs of individual family members of service personnel receiving inpatient rehabilitation services at the Polytrauma Rehabilitation Center (PRC) located within the Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia.

Chapter II

Review of the Literature

The review of the literature is divided into five sections. The first section describes the polytraumatic injuries that are being treated at the McGuire VA Medical Center in Richmond, Virginia. The second section describes the Polytrauma Rehabilitation Center (PRC) at the McGuire VA Medical Center and reviews the developing programs within the Veteran Health Administration to care for family members of and individuals who have suffered a polytrauma. The third section reviews literature pertaining to family members of individuals with a polytrauma, drawing heavily from literature related to family members of individuals with traumatic brain injury. This section is divided into four subsections: family member reaction to brain injury, risk factors for poor adjustment, family needs following a brain injury, and an overview of interventions for families of individuals with a brain injury. The fourth section reviews a contextual model of family stress management, an applicable theoretical approach for working for families of military personnel who sustain a polytrauma. Finally, the fifth section examines families in the military system and the applicability of a contextual model of family stress management to the family members of individuals with a polytrauma who are being treated at the Polytrauma Rehabilitation Center at McGuire VA Medical Center.

Polytraumatic Injuries

Polytraumatic injuries treated at the Polytrauma Rehabilitation Center (PRC) at the Hunter Holmes McGuire VA Medical Center in Richmond, Virginia are complex and difficult to treat. The inclusion of a brain injury complicates the treatment of all other

injuries if faculties needed for treatment and rehabilitation have been affected. Affected areas may produce deficits in functioning related to vision, hearing, balance and motor control, emotion and impulse regulation, and internal organ functioning. Treating a patient on the PRC requires constant attention to the brain injury and its influence on all other systems. A better understanding of the epidemiology and nature of traumatic brain injury will facilitate an appreciation of the medical and psychological challenges involved in a polytrauma.

Brain injuries are divided into three types: focal cortical contusion (e.g., from a gunshot wound), diffuse axonal injury (e.g., from a motor vehicle accident), and hypoxic/ischemic (e.g., from anoxia, stroke, cardiac arrest; DVA, 2004). Focal cortical contusions and diffuse axonal injuries are classified as traumatic brain injuries (TBI) and are most commonly treated at the PRC in Richmond, Virginia. They are typically caused by an explosion in Iraq or a motor vehicles accident in the United States. In some cases, an explosion in Iraq may cause a subsequent motor vehicle accident. Mechanisms of injury are divided into primary and secondary mechanisms. Primary mechanisms of injury occur at the moment of the impact and as a direct result of the traumatic incident (explosion or accident) and include contusions and lacerations of the brain surfaces, diffuse axonal injury (stretching of axons all over the brain), diffuse vascular injury (bleeding in multiple areas of the brain), and cranial nerve damage (Elovic, Baerga, & Cuccurullo, 2004). A secondary mechanism of injury occurs after the initial trauma, usually within 12 – 24 hours, may be preventable, and may include additional bleeding, brain swelling and/or edema, damage secondary to a lack of oxygen, infection, and the production of free-radical molecules (Elovic et al., 2004). Specific problems secondary

to a head injury may include post-traumatic epilepsy, medical and orthopedic complications, movement disorders, communication disorders, cognitive deficits, behavioral and psychiatric conditions, deficits in activities of daily living, and sexual dysfunction (Brooks, 1990; DVA, 2004; Elovic et al., 2004; Griffith, Cole, & Cole, 1990; McNey, 1990; Miller, Pentland, & Berrol, 1990; Rosenthal & Bond, 1990).

Brain injuries are also divided into two general categories: penetrating head injury and closed head injury. With respect to the conflict in Iraq and Afghanistan, a penetrating head injury may be caused by a projectile entering the brain, such as a bullet or piece of shrapnel; a closed head injury may be caused by the force of a change in air pressure caused by an explosion or the force of the brain being slammed against the inside of the skull. Taber, Warden, and Hurley (2006) report that exposure to an explosion causes primary, secondary, and tertiary blast injuries. Primary blast injuries occur from the wave of the blast that produces atmospheric pressure changes. Secondary blast injuries occur from people being hit by objects put in motion by the blast. Tertiary blast injuries are caused by people being forcefully put in motion by the blast. Close to 90% of all injuries treated at the second echelon of medical care in Iraq occurred as a result of an improvised explosive devise (IED) or mortar explosion and close to 50% of those injuries involved the head (Taber et al., 2006).

The level of severity of head injuries are divided into three general categories: mild, moderate, and severe. The severity of the injury is typically defined according to one of three indices: score on the Glasgow Coma Scale (GCS; Teasdate & Jennett, 1974), length of loss of consciousness (LOC), and length of post-traumatic amnesia (PTA). The GCS is a 15-point scale based upon ratings of the patient's best eye opening, motor, and

verbal responses (see Table 1). LOC is the length of time the patient does not respond to external stimuli, with longer LOC positively correlated with severity (DVA, 2006). PTA is the time interval from when a person regains consciousness until he or she is able to form memories for ongoing events (DVA, 2006). Persons with a mild traumatic brain injury (MTBI) experience an altered or LOC for less than 30 minutes, present with a normal CT/MRI scan, GCS of 13-15, and have PTA less than 24 hours. Persons with a moderately severe TBI experience a LOC for less than 6 hours, present with an abnormal CT/MRI scan, GCS of 9-12, and have PTA less than 7 days. Persons with a severe TBI experience a LOC of greater than 6 hours, present with an abnormal CT/MRI scan, GCS of less than 9, and have PTA greater than 7 days. The level of severity of the head injuries, measured by these indices and subsequent sequelae, dictate the treatment protocol once the person is medically stable. Cognitive and behavioral functioning is commonly measured by the Rancho Los Amigos Levels of Cognitive Functioning Scale (RLAL; Hagen, Malkmus, & Durham, 1972). There are eight levels to the scale listed in Table 2. These ratings are frequently used in clinical settings and are used as a standardized way to quantify the patient's level of function and changes in functioning.

Since the escalation of the use of IEDs and mortars in Iraq (circa March 2004), battlefield medicine and Level V military treatment facilities continue to respond and develop treatment protocols for military personnel presenting with mild, moderate, and severe head injuries. To better treat the range and distinct features that separate the sequelae of mild, moderate, and severe head injuries, the VA PRC in Richmond has recently added two new specialized treatment protocols to their existing treatment protocol. The PRC is admitting military personnel with mild, moderate, severe, and very

severe head injuries to their program. Time spent on the PRC represents one phase (in-patient rehabilitation) of four in the injury recovery process. The four phases are acute, in-patient rehabilitation, return to home/out-patient rehabilitation, and long term (Rotondi, Sindule, & Balzer, 2007). The acute phase encompasses all experiences prior to being admitted to the PRC. Admission to the PRC and time spent on the PRC up to discharge represents the in-patient rehabilitation phase. Enrollment in the out-patient polytrauma program represents the return to home phase. The long term phase begins after patients are either returned to duty, medically discharged and integrated into the community, or established in a long-term (age-appropriate) nursing facility.

Understanding the typology of the injury, will provide a better understanding of the how the injury fits into the family and the family's adjustment to the injury. Frequently used to classify illness, a psychosocial typology can also be applied to an injury, conceptualizing distinctions of onset, course, outcome, and degree of incapacitation of the injury (Rolland, 1989). Onset is either gradual or acute; course is either constant, progressive, or episodic; outcome relates to whether the injury will be the most likely cause of death; and incapacitation relates to how much the injury impacts pre-morbid functioning (Rolland, 1989). Variations in typology indicate variations in how the injury will affect the family. For example, polytraumatic injuries have a sudden rather than a gradual onset, requiring family members to more rapidly mobilize crisis-management skills (Rolland, 1989). This information also has implications for deciding which caregiver literature may be generalized to the PRC population. When generalizing caregiving literature, the more closely matched typology of the injury or illness, the more generalizable the information.

Polytrauma Rehabilitation Centers and Developing Programs

Operating under a national Memorandum of Agreement (MoA) with the Department of Defense (DoD), four Department of Veterans Affairs (DVA) lead Polytrauma Rehabilitation Centers (PRC) provide specialized rehabilitation care to severely injured personnel requiring inpatient rehabilitation (VHA Directive 2005-024, June 08, 2005, Polytrauma Rehabilitation Centers). One of these four centers is located at the Hunter Holmes McGuire VA Medical Center. The mission of the Polytrauma Rehabilitation Center is to provide comprehensive inpatient rehabilitation services for individuals with complex cognitive, physical and mental health sequelae of severe and disabling trauma and provide support to their families. Presently, the PRC at McGuire VA Medical Center is 20-bed unit, with an average census of nine patients at any given time. Beds are held open to quickly accommodate Operation Iraqi Freedom/Operation Enduring Freedom personnel from Walter Reed Army Medical Center (WRAMC) and the National Naval Medical Center (NNMC). The length of stay varies depending on the level of severity of the injury.

Several programs are developing to accommodate PRC patients who have brain injuries that fall in the mild and very severe categories. All patients are treated using a multidisciplinary team approach to treatment and are tracked into one of three developing programs. The main program of treatment typically includes patients with a RLAL of 3-7 (S. [medical director], M.D., Medical Director, Polytrauma Rehabilitation Center, personal communication, February 1, 2007). Patients who are considered to have a mild traumatic brain injury (MTBI, RLAL of 7-8) are enrolled in a 'transitional' program, either initially or after improvements gained during inpatient rehabilitation. These

patients are treated using an exercise-based rehabilitation model, traditionally used with sport-related post-concussive injuries. Patients who have a very severe to extremely severe brain injury with a RLAL of 1-2 are enrolled in the 'emerging conscious' (EC) program that focuses on multidisciplinary sensory stimulation. The goal of this program is to promote wakefulness and consciousness in the patient. Funding was recently released for renovation and new construction to begin at McGuire VA Medical Center for a separate transitional rehabilitation program (for MTBI patients) and a separate age-appropriate long-term nursing care unit with an active sensory stimulation rehabilitation program for patients in the EC program.

In addition to the four PRCs, there are 21 outpatient polytrauma network sites (PNS). Once discharged from the PRC, depending on the patient's needs, he or she may receive outpatient treatment at one of the 21 PNS locations. Either way, a social worker from the PRC will be assigned to follow the patient for one-year following his or her discharge from the inpatient rehabilitation unit. This social worker is responsible for making sure the patient has a seamless transition to his or her next level of care and that care continues as needed.

Services for family members are developing as well. The PRC has an on-going family education program. This one-hour per week program is geared toward educating family members on different aspects of polytrauma rehabilitation. Topics include in-depth introductions to all the different disciplines on the treatment team, community resources for TBI, an introduction to veteran benefits, information pertaining to military medical evaluation boards, and stress management. Upon admission, family members are given a family education manual. This manual is a consolidation of information and

resources from the Defense and Veterans Brain Injury Program (DVBIC) and the Brain Injury Association of America (BIAA). The PRC has a family lounge with recreational reading materials, fish tank, and television and a family resources room with two internet-capable computers, brain-injury and veteran benefit information, and other educational information and resources. Family members are also provided supportive therapy on a case-by-case basis by the unit's rehabilitation psychologist. There currently are no structured group activities or interventions for families as part of the PRC family programming. Family members receive supportive therapy as part of the patient's treatment; no clinical or therapeutic services are independently available to family members.

Family Members and Polytrauma

A continuum of care for persons with severe head injury includes an "overlapping" process of resuscitation, assessment, management, rehabilitation, and evaluation of functional outcomes (Miller, 1990, p. 75). Miller (1990) stresses the importance of a multidisciplinary team approach to rehabilitation assessment and treatment of the patient, also highlighting family involvement and intervention as a critical component of the patient's treatment plan. Components of family functioning and involvement with care are reported to influence brain injury sequelae and quality of life for the person with the injury (Duff, 2006; Rosenthal & Young, 1988), but the injury is reported to influence family functioning and well-being as well. (Livingston & Brooks, 1988).

Impact of polytrauma on the family. The impact of a brain injury on family changes over time. Lezak (1986) outlined six stages (or reaction patterns) families

experience after a brain injury. These stages are defined according to (1) time since hospitalization, (2) family member's perception of patient, (3) family member's expectation, and (4) family reaction. Although arranged by criteria, these stages do not operate on a linear continuum. Many families may skip stages or cycle back though previous stages (Lezak, 1986). Family members may react to the injury with happiness (that the patient has survived and/or has left the hospital), bewilderment, anxiety, discouragement, guilt, depression, entrapment, and mourning. Carnes and Quinn (2005) describe a reaction process consisting of two phases: adjustment and adaptation. They note that family functioning and mechanisms used to maintain the status quo in the family system preinjury are central to how a family will react and adjust to the injury and change over time. Thus, if family members were able to effectively solve problems before the injury, they will be more likely able to do so in the face of crisis.

Perlesz, Kinsella, & Crowe (1999) critically reviewed the literature pertaining to the impact of TBI on the family and found that the impact of the injury varied according to the relationship the individual family member has with the injured member. However, to different degrees, it is typical for all family members to be affected by stress, resulting from coping with the acute crisis of the traumatic injury and the injury sequelae that follows (Brooks et al., 1986; Carnes and Quinn, 2005; Lezak, 1986, 1988; Livingston & Brooks, 1988; Verhaeghe, Defloor, & Grypdonck, 2005). Stress, also referred to in the literature as *strain* and *burden*, is a consistent variable prevalent in the literature on the impact of injury on family members. In addition to experiencing increased stress, family members may experience decision-making problems, attention and concentration difficulties, social isolation, and feeling overwhelmed as a result of the patient's injury

(Curtiss, Klemz, & Van der Ploeg, 2000; Kreutzer, Gervasio, & Camplair, 1994; Perelez & O'Laughlan, 1998). Severe injury may have a significant impact on family and individual functioning, producing a variety of family and individual symptoms of distress. Injuries, families, and individuals are diverse and therefore, family members and individuals will adjust and adapt to a severe injury in a variety of ways. Understanding family and individual factors for adaptive or maladaptive adjustment will help identify those families and family members who will be more severely impacted by a polytrauma.

Risk Factors for Poor Adjustment. Risk factors for poor adjustment are divided into three categories: injury characteristics, patient characteristics, and family characteristics (Serio, Kreutzer, & Gervasio, 1995). Changes in personality and behavioral functioning in the patient following a polytrauma, which fall under the category of injury characteristics, are reported as being most distressing to family member functioning (Brooks et al., 1986; Carnes & Quinn, 2005; Elliott, Shewchuk, Richards, 2001; Mauss-Clum & Ryan, 1981). More specifically, families of patients that are functioning at a Rancho Los Amigos Level of 4 (confused and agitated with a heightened state of activity, confusion, disorientation, and lacking self-awareness) are expected to experience increased psychological distress and decreased family functioning in comparison with family members in Levels 1 through 3 or 6 through 8 (Table 1; Carnes & Quinn, 2005).

Under the category of family characteristics, status as a primary caregiver places an individual at increased risk for problems with distress and illness (Zarski, DePompei, & Zook, 1988). Because mothers and wives most often assume caregiver roles, it follows

that the relationship (being a mother or wife) to the person with the brain injury may place an individual at increased risk for poor outcomes. However, traumatic brain injury appears to have a greater impact on partners than parents (Verhaeghe et al., 2005). Wives report experiencing frustration, irritability, annoyance, depression, anger, decreased time for themselves, financial insecurity, and social limbo (Mauss-Clum & Ryan, 1981; Wood, Liossi, & Wood, 2005). Also under the category of family characteristics, poor family functioning pre-injury may place families more at risk for poor adjustment (Carnes & Quinn, 2005). Zarski and colleagues (1988) report risk factors for poor adjustment are more related to family resources and coping styles than they are to the injured family member's limitations.

Family Needs Following a Polytrauma. Injury, patient and family characteristics have been identified as potential risk factors for poor adjustment. It is therefore important to identify these variables in the assessment of family needs post-injury. Methodological issues pertaining to the assessment of families reverberate though the literature (Duff, 2006; Livingston & Brooks, 1990; Perlesz et al., 1999; Sander, 2005) as studies vary greatly in the extent to which they identify and control for these characteristics. Recent efforts have been made to address methodological concerns found in the literature. Specifically, efforts have been made to standardize the demographic variables identified and assessment measures used in their research on family needs following a brain injury (Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Kreutzer et al., 1994; Mead, Taylor, Kreutzer, Marwitz, & Thomas, 2004; Serio et al., 1995). The assessment measure that has been consistently used across several studies is the Family Needs Questionnaire (FNQ; Kreutzer, 1988), which was developed to identify family needs, level of

importance of those needs, and whether or not each need has been met. Clinical experience, extensive interviews with family members, and adaptations from existing questions were used to develop the questionnaire (Kreutzer et al., 1994). The FNQ includes six discrete scales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care (Serio et al., 1995). First, participants are asked to rate the importance of a listed need using a Likert-type scale rating from 1 to 4 (not important, slightly important, important, very important). Next participants are asked to indicate if that need was met, partially met, or unmet. This questionnaire has been used with brain injury and spinal cord injury populations. Serio and colleagues (1995) report the FNQ subscales are reliable based on a factor analytic study conducted that revealed alpha reliability coefficients for the six subscales ranging from .78 to .89. The following four studies (described below) report similar demographic data and use the FNQ to assess the needs of families following a brain injury or spinal cord injury.

Kreutzer and colleagues (1994) report that family members of patients with a primary diagnosis of brain injury experience feelings of being misunderstood, isolated, and unsupported. They administered the Family Needs Questionnaire (FNQ; Kreutzer, 1988) to 119 family members of individuals who had mild, moderate, or severe injuries in the acute and post-acute states of injury. Demographic information included gender (70% female), ethnicity (75% white), age (ranged from 17 to 76), the motor subscale of the GCS, days in coma (range = 0 to 180), and time since injury (range = .2 to 97.5 months). A computation of percentages was used to determine within the sample what needs were important and/or not important and the extent to which needs were met and/or

not met. The top 10 items in the *Important/Very Important*, *Not Important*, *Met* and *Not Met* categories were reported. Health information needs dominated the *Important/Very Important* category, with percentages ranging from 94-99. *Not Important* needs included instrumental support, and emotional support items, with percentages ranging from 13-32%. *Met* needs included all scales, with percentages ranging from 67-79. Needs most frequently rated as *Not Met* included emotional support, and instrumental support, with percentages ranging from 26-41. Results of this study suggest family needs change over time and additional psychological, social, and peer support services may benefit families (Kreutzer et al., 1994).

Serio and colleagues (1995) assessed family needs as part of a larger study designed to predict family needs after TBI. Participants were at least two years post-injury and were similar to the general TBI population: predominantly male, the leading cause of injury was a motor vehicle accident, 81% were white, and 19% were minorities (mostly African American). The average age at the time of injury was 32 and duration at the time of injury ranged from one to 195 days. Family members were parents, spouses, and significant others who were predominantly the primary caregiver of the person with a TBI. Relatives' demographics included socioeconomic and education backgrounds, age ranging from 19 to 74 years, gender (72% female), relationship to the person with the TBI (spouses = 43%, parents = 36%, siblings = 7%, live-in partners = 7%, close friends = 5%, and adult children = 3%). Hours spent caring for the patient ranged from 1 to 16 hours per day. Results show that 55% of family needs were rated as being *Met*. Forty-two percent (42%) of Emotional Support items were rated as *Not Met* with one third of Emotional Support needs rated as *Not Met* and 14% of Medical Information needs rated

as *Not Met*, suggesting relatives report receiving enough medical information, but not enough emotion support (Serio, 1995).

Kolakowsky-Hayner and colleagues (2001) used the FNQ and quality of life questions, and reported long-term family caregiver needs in a brain injury population. Demographics for the caregiver (n = 57) and person with the TBI (at least four years post-injury) included the following items: race, gender, employment status, highest level of education, relationship to the patient. Similar patient demographics were included in the study, but also included how they were injured, time since injury, post-traumatic amnesia (PTA), pre-injury and post-injury employment status, education and marital status. Health Information (51.93%) and Involvement with Care (47.93%) needs were endorsed most often as *Met*. Instrumental Support (31.52%) and Professional Support (28.38%) needs were endorsed most often as *Not Met*. The proportion of needs rated as *Met* exceeded the proportion of need rated as *Not Met* for each scale. Findings of this study suggest that participants' needs change over time and that they became more dissatisfied with the quality of their lives post-injury (Kolakowsky-Hayner et al., 2001).

Meade and colleagues (2004) evaluated family member needs of an inpatient spinal cord injury (SCI) population using the FNQ (Kreutzer, 1988). Study participants (n = 17) were identified by the patient as the primary caregiver and ranged in age from 18 to 83 years. They were 35% mothers, 29 % wives, 6% husbands, 12% sisters, 12% girlfriends, and 6% other, and 84% lived with the patient at the time of injury. Time since injury ranged from 13 – 76 days, with education, occupation, and socioeconomic variables reported, as well. Health information needs were rated as most important followed by emotional support, professional support, community support network, and

involvement with care, and instrumental support needs. The extent to which needs were rated as met ranged from 43-68% across all six scales, with values for health information, community support networks, and involvement with care needs all greater than 60%. Emotional support and instrumental support needs had mean percentages lower than 50%. Findings from this study suggests the FNQ may be appropriate for identifying the needs of family members of person with SCI, family education is important during rehabilitation, and might also be used as a program evaluation tool (Mead et al., 2004).

To supplement the use of a quantitative measure of family needs, Rotondi and colleagues (2007) recently report using a semi-structured interview to investigate family member needs after they reintegrate into the community. The authors reported themes and specific needs of primary support persons and person who have experienced a traumatic brain injury by phase (acute, in-patient rehabilitation, return home, and long term) and identified themes as they occurred and varied across these phases. Themes that occurred in the acute and in-patient rehabilitation phases included: quality of services, involvement in decision making, discharge from hospital, support from professionals and employer support.

In sum, these studies provide valuable information related to family needs following a severe injury. Further, methodological issues are being addressed by consistent inclusion of the FNQ and similar demographic variables. Taken together, these findings suggest that having a sound body of information pertaining to the needs of families following a severe injury can have a profound effect on the standard of care for families of persons with severe injuries. Conclusions can be drawn with greater

confidence because of the quality of this research. From this information, interventions may be developed and implemented to address identified needs of families post-injury.

Family Intervention Following a Polytrauma. Family intervention studies are plagued with similar methodologically challenges as studies that assess the needs of these families (Oddy & Herbert, 2003; Sander, 2005). Muir, Rosenthal, and Diehl (1990) first introduced methods of family interventions to the rehabilitation arena by outlining six categories of interventions and four methods of assessing family systems. The intervention methods include: patient-family education, family counseling, family therapy, behavioral family training, respite care, and family support groups. The assessment measures of family intervention include: informal observational techniques, formal observational techniques, self-report measures, and behavioral response products. However, Muir and collegues (1990) present little information about the use of various assessment methods with a TBI population because work in these areas was just emerging at that time.

Just over a decade later, Sander (2005) published a chapter that reviewed existing evidence for the efficacy of interventions with families of persons with TBI. She categorized interventions into three categories: education, support, and formal therapy and only included studies that used formal outcome assessments. She then assigned each category of study into one of four classes with respect to the evidence it presented. Thus, each study was classified according to the type of intervention and the type of evidence it reported. She analyzed ten studies that used formal outcome assessments, spanning eight years, and concluded "research to date shows that evidence for the effectiveness of intervention for caregivers after TBI is minimal" (Sander, 2005, p. 168). She reported

common methodological limitations of existing studies include small sample sizes, multiple outcome measures, no control for Type I error, inclusion of persons with various etiologies and coexisting medical problems, recruitment and characterization of samples, lack of control for premorbid functioning, and choice of assessment measures that was not guided by a theoretical model. (Sander, 2005). She directs future researchers to account for the fact that one type of intervention may not be effective for all caregivers and that caregiver needs and demographics should be screened prior to the application of an intervention.

The development and implementation of family interventions based on the needs of families has shown to be effective (Chien, Chiu, Lam, & Ip, 2006). The Brain Injury Family Intervention (BIFI; Kreutzer & Taylor, 2004) was developed from information gained from the FNQ and the FNQ is used as the primary outcome measure of the intervention. The session topics are chosen specific to each participant, based on the items they endorse on the FNQ pre-intervention. Preliminary results are based on FNQ and Brief Symptom Inventory (BSI; Derogatis, 1993) endorsements pre- to post-inventory, and a qualitative satisfaction measure. Data from the FNQ show positive changes in needs that are rated as *Met* pre to post-intervention. Symptoms of emotional distress were reduced as measured by the depression, anxiety, and global severity index of the BSI. Satisfaction with the program, as measured by a qualitative satisfaction questionnaire suggests participants were very satisfied with the intervention.

Based on the growing body of information surrounding the FNQ and BIFI, Marks and Daggett (2006) developed a critical pathway for meeting the needs of families of inpatients with severe traumatic brain injury. They propose that interventions with

families should begin as soon as possible and continue "across the continuum of care" that is divided into "four phases of care (Phase 1 – NSICU admission, Phase 2 – acute critical care and hemodynamic stabilization, Phase 3 – acute critical care/mobility and weaning, and Phase 4 – post-acute care/pre-rehabilitation or pre-discharge)" (Marks & Daggett, 2006, p. 85) and change as patients progress though phases of recovery. Currently, the authors report there is only unstructured, anecdotal information from health care providers alluding to the efficacy of the critical pathway intervention.

Families of service members who are injured in Iraq or Afghanistan are typically not present for Phase 1 and 2 as described above due to the fact these phases typically take place outside the United States. This underscores one of the many differences between a military subculture and the population it serves. The identification and understanding of the context surrounding battle- and non-battle-related injuries of military service personnel and the treatment of their families is an important of part of understanding their experiences and how they manage their stress.

A Contextual Model of Family Stress Management

Stress is highly researched and broadly defined. Within the variety of definitions, this complex psychological and physiological phenomenon called stress is best defined generically as a stimulus and a response. Stimuli vary, responses vary, pre-exposure baseline data vary, and long-term effects of exposure to stress vary. There are even outlined stages of stress that vary. Another component of this multifaceted equation is the coping mechanism or multiple coping mechanisms people use that vary from unconscious biological responses to conscious and overt problem-focused actions. The basic and applied research associated with stress is just as varied as the components that

make up the stress equation. What is most important across all research is simply how to best preserve and promote the short and long-term health of the individual by providing appropriate interventions at appropriate times (Salovey, Rothman, Detweiler, & Steward, 2000).

Family stress theory emerged from the general stress and coping literature (McCubbin, Cauble, & Patterson, 1982). As with individuals, families experience stress related to developmental changes in the family that all families face over the life-span. These *normative events* (McCubbin et al., 1982) and developmental changes or movement from one phase of life to another may look different between different groups or cultures, but all families experience several life events, as well as developmental changes over the life span. *Nonnormative events* are life events that are typically unexpected, such as an untimely death, an automobile accident, diagnosis of a terminal illness or loss of employment. For military families, a training deployment may be considered a normative event, but a combat-related deployment and/or the loss of life or injury as a result of that deployment are *still* considered a nonnormative event.

McCubbin and colleagues (1982) report that the emergence of family stress theory developed as a result of four lines of research: (1) the association between life stress and illness, (2) potentially dysfunctional coping strategies may be developed, taught, and reinforced within the family, (3) not all individuals and family units become victims of stress, and (4) social support as a buffer to adverse effects of stress. The evolution of family stress and crisis theory began with the advancement of the *ABCX* model of family response to stress (Hill, 1949) and was expanded by McCubbin and Patterson (1982) into the *Double ABCX* model of family stress, a more dynamic model

that includes what families do over time to adapt to a crisis and the interaction of variables such as multiple ("pile-up") stressors and specific coping behaviors (p. 3). The *ABCX* model, developed out of research on war-induced separation and reunion, includes the following framework: A (event) – interacting with B (the family's crisis resources) – interacting with C (family's interpretation of the event) – produces X (the crisis; Hill, 1958). The *Double ABCX* model expands this model over time and includes post-crisis adaptation as shown here (McCubbin & Patterson, 1982). See Figure 1.

Boss (2002) further adapts this model to include the following ideas: (1) there is no "normal" American family, (2) contexts surrounding families influence their ability to manage stress or recover from crisis, and (3) more diverse studies are needed within the family stress and crisis literature (p.2). She also underscores the importance of the highlighting resilience in the family stress field and the recognition of spirituality and faith as important coping mechanisms in family stress management. She defines resilience as "the ability to stretch (like elastic) or flex (like a suspension bridge) in response to the pressures and strains of life" (Boss, 2006, p.48). She defines *family* as a "continuing system of interacting persons bound together by processes of shared rituals and rules even more than by shared biology" (Boss, 2002, p.18). These families have an internal context and an external context, with the internal context composed of dimensions the family can control and the external context composed of dimension the family cannot control. The addition of two new variables, ambiguous loss and boundary ambiguity, to the model moves it from a linear model to one that is more contextual, complex, and circular (Boss, 2002, p. 30), emphasizing resilience and health more than pathology.

The research-based theory of ambiguous loss is "a less pathology-based lens for viewing unresolved loss and its outcomes of anxiety, somatic symptoms, and relational conflict" (Boss, 2006, p. 3) with interventions tailored to fit unique needs in unique contexts. Ambiguous loss occurs when someone is psychologically present, but not physically present, or physically present, but not psychologically present. In a society that values mastery, it may be painful, confusing, shocking, distressing, and even immobilizing to experience ambiguous loss because there is no closure or recognition of loss (Boss, 2006). Clinically, the goal of therapy for someone who is experiencing a traumatic and/or ambiguous loss is not acceptance and closure, but learning how to live comfortable with ambiguity. As such, clinicians are also encouraged to model comfort with ambiguity. A mother of a son with a brain injury who is minimally responsive is in limbo with her thought, hopes, and emotions as he continues to breath on his own, but is minimally responsive. Someone with a mild brain injury may appear to be the exactly the same as she was pre-injury, but experience agitation, impulsiveness, irritability, and short-term memory deficits. Family, friends, and co-workers may feel distress associated loss of the person they knew prior to the injury, but confused by the relatively unchanged physical appearance and high level of functioning in the person.

Boundary ambiguity, not knowing who is in or out of the family or relationship, becomes a risk factor for distress when it is high (Boss, 2006). This specifically relates to the assignment of roles with in the family and tasks on being completed due to the reassignment of roles and the dropping of tasks. See Figure 2 for a pictorial representation of how boundary ambiguity and ambiguous loss fit in the family stress model. Boss (2006) highlights that boundary ambiguity can been viewed as both

objective and subjective, as most everyone would agree that receiving a phone call that a loved-one has been severely injured is objectively stressful, there are subjective elements that will determine the degree of stress and trauma experienced. How an individual or family views and manages objective and subjective stress influences resilience. Boundary ambiguity may come more into play with blended and subsequently unblended families. Marriages, divorces, remarriages and separations that an individual is able to successfully manage and work around pre-injury, may be a significant source of distress for all involved when all must rally around one hospital room at the same time. Clearly defining roles, traditional and non-traditional, is helpful when managing a traumatic or ambiguous loss.

Military Families, Trauma, Loss, and Resilience

A polytraumatic injury may be classified as an ambiguous loss and even a traumatic experience, given the shock of the sudden notification and the fact that the service member has survived, but survival and long-term prognosis is uncertain for an extended period of time. Family stress and resilience models have been used with military populations since the end of World War II and are currently being used when preparing family members to endure the hardships of duty-related separations (Hill,1976; Wiens & Boss, 2006). Requirements for managing stress, specifically for military families, involve the abilities to be resilience and live comfortably with ambiguity; bending without breaking and tolerating unknowns (Wiens & Boss, 2006). There are multiple family resources that function as protective factors during a military separation: (1) flexible gender roles, (2) active coping strategies, and (3) community and social supports (Wiens & Boss, 2006). Risk factors for poor adjustment in military families

include: (1) families or family members that are alone or without a unit affiliation, (2) families that are young and inexperienced, (3) families with a pile-up of stressors, additional challenges, and/or traumas (Wiens & Boss, 2006).

As it relates to military deployments, separations, and reintegration with a medically and/or mentally healthy returning service members, the Contextual Family Stress Model emphasizes the families' perceptions of the separation and how these perceptions are mediated by the family's contextual factors. Adding to the complexity of the model are the unique characteristics of each family, generation, ethnicity, gender, religion, and within-group differences that exist within the larger military culture (branch of service, rank, specialty, and time in service; Wiens & Boss, 2006). To collect specific information pertaining to the military families from within their context, Wiens & Boss (2006) conducted interviews in 2004 with National Guard (military) families in the upper Midwest who had endured a military separation for 6 to 18 months. Following these interviews, their recommendations for maintaining resilience among family members include: (1) involve the entire family in the readiness process (to reduce risks of family trauma and crisis and the effects of catastrophic separation), (2) disseminate educational materials to all service members and their families, (3) maintain a working relationship with auxiliary members of a military community who may be called upon to help during times of crisis and military deployments, (4) organize and encourage families to participate in a "family buddy" relationship parallel to the service member's "battle buddy", (5) maintain those buddy connections before, during, and after the deployment, (6) maintain unit level family support groups before, during, and after the deployment, (7) seek marriage and family therapy and other therapy-led psycho-educational groups

(p.34). This chapter is one of several chapters in one volume (Vol. 3: *The Military Family*) of a multi-volume series of books recently published by the lead researcher from within the Department of Defense's Walter Reed Army Research Institute. Another chapter in the volume discusses how military spouses cope with fear and the reality of service member injury and death (Chapter 4; Wright et al., 2006). The chapter skips directly from talking about separation fear to coping with the reality of service member death. Notably, there is no information about coping with severe injury, highlighting the lack of information available to families and clinicians pertaining to the reunion of a severely injured service member with their families.

Military Family Members and Polytrauma. Service personnel who are medically evacuated from a combat zone and their family members face unique challenges in addition to the typical redeployment and reintegration issues many returning service personnel face (MacDermid, 2006). Injured service members are not welcomed home with a parade, but are quietly and unassumingly wheeled into military treatment facilities during hours of darkness. From within the military and TBI professional community, Cozza, Chun, and Polo (2005) used unstructured clinical observations of children and families during the ongoing war in Iraq from Walter Reed Army Medical Center to highlight the unique challenges families of injured service members face, noting there are few objective data that may help doctors, clinicians, and other health service providers understand the impact injury has on a family during wartime. This report focuses on the impact of severe injury on the children of injured service members and calls for more research on this population with an emphasis on the strengths of military families and that although the general public's concern is welcomed, it is often misplaced. Even with this

information and the extensive narrative and visual offerings from the general media, many questions about how military families are coping with severe injuries remain unanswered. Answers to questions about military family needs following a polytrauma will inform clinical practice, intervention development and affect funding and policies related to this population.

The Present Study

Kreutzer and colleagues (2002) confirm that the rehabilitation literature provides an extensive amount of information pertaining to family members' reactions to injury and changes in family functioning, indicating there are many common experiences family members of individuals with brain injuries face. Less is known about the unique needs and lived experiences of military families following a polytrauma. The Polytrauma Family Needs Assessment Study, funded by the Department of Veterans Affairs, is timely and is presently informing the development of a national multi-site family needs assessment study that will ultimately serve as the impetus for the development of a structured family intervention program based on individual family member needs as they change over time.

Chapter III

Method

A cross-sectional, mix-method, sequential exploratory design was used to test the feasibility and applicability of a family assessment method while exploring the experiences and needs of family members of service personnel receiving inpatient rehabilitation services.

Participants and Procedure

Data were collected from individuals participating in their injured family member's rehabilitation at the Polytrauma Rehabilitation Center (PRC) at the Hunter Holmes McGuire VA Medical Center in Richmond, Virginia. Potential participants were introduced to the study by the unit's rehabilitation psychologist guided by a brief information script (Appendix A). As part of the patient's multidisciplinary treatment plan, the rehabilitation psychologist meets with primary family members to assess levels of emotional distress, provide brief psychological interventions (through education and support), and make recommendations to the treatment team in reference to how best to support individual family members given their individual circumstances. If family members were interested in participating in the study, the rehabilitation psychologist notified the Principal Investigator (PI) of the study. The PI then approached the identified family member to schedule an appointment for them to learn more about the study. Typically, family members wanted to hear about the study at that time and the study was then explained to the potential participant by the PI (Appendix B). Any questions were answered and potential participants were given a written copy of the informed consent (Appendix C) to read, as it was reviewed with them by the PI.

Potential participants were informed that they could take as much time as they desired to review the informed consent form, and that they did not have to make a decision about whether to participate at that time. Once informed consent was obtained, the PI scheduled two appointments at the family member's convenience.

During the first appointment, three quantitative instruments were administered: a demographics survey, the Brief Symptom Inventory - 18 (BSI-18; Derogatis, 2001), and the adapted version of the Family Needs Questionnaire, the Family Needs Questionnaire – Military (FNQ-M, Jeffrey S. Kreutzer, PhD, ABPP, personal communication, March 6, 2006). During the second appointment (Session 2), a standardized open-ended interview was conducted (Appendix G) and tape recorded. Following the interview, a second BSI-18 was administered to the participant. Both sessions took place in a conference room on the unit.

Specifics about Participants

This section will provide a brief description of each participant and details about the setting and the PI's observations and reflections of time spent with the participant. The period after an interview is "critical to the rigor and validity of qualitative inquiry" (Patton, 2002, p. 383). All names and identifying information have been removed to protect the anonymity of the participants. Participant demographics and patient level of injury severity as reported by the participant are reported. The direct collection of patient medical information was not conducted for this study. Generally, most patients admitted to the PRC in Richmond have PTA greater than or equal to one day, placing them in moderate, severe, and very severe injury categories. Family members were asked to rate the patient's level of injury severity on a scale of 1 (not severe) to 5 (very severe). The

setting remained the same for each participant. The unit conference room was used for both sessions for each participant. The conference room is on the unit and has a large table, modern and comfortable office chairs and no windows. The unit rehabilitation psychologist was present in the room for the first six interviews. She sat behind the participant, but some participants, at times, would turn to include her in the conversation.

Participant #1 is a 30 year-old, Caucasian, college-educated, mother of two young children. She is the wife of an active duty, Army sergeant who was severely injured in Iraq. She discontinued working after her husband deployed so that she could spend more time with her daughters in the absence of her husband. After she was notified that her husband was injured she traveled to meet her husband at a military treatment facility within the United States. Her two children remained their home under the care of her grandmother. She rated her husband's injury severity level as 3 out of 5.

Participant #2 is a 48 year-old, employed, Caucasian, female, who completed some college following high school. She is the mother of an active duty, Army sergeant who was severely injured in Iraq. After she was notified her son was injured, she traveled to meet her son in Landshtul, Germany who was later transferred to a medical treatment facility within the United States. She rated her son's injury severity level as 5 out of 5.

Participant #3 is a 46 year-old, self-employed, Caucasian male who completed some college following high school. He retired as a senior non-commissioned from the Navy. He is the father of an active duty, Navy corpsman who was injured in a motor vehicle accident in the U.S. while on leave (vacation). After he was notified that his son

was injured, he traveled to a civilian hospital to meet his son who was later transferred to a military treatment facility. He rated his son's injury severity level as 5 out of 5.

Participant #4 is a 29 year-old, Caucasian mother of two young children with some post-high school education. She is the wife of an active duty, Army sergeant who was severely injured in Iraq. She was working as a volunteer and taking college classes at the time of her husband's injury. After she was notified that her husband was injured, she traveled from outside the United States where the family was stationed to meet her husband at a military treatment facility within the United States. Her two children initially remained at home under the care of her friends. She expressed concerns about introducing her children to their father for the first time following his injury and subsequent redeployment. Staff and the participants referenced the *Our Heroes Handbook* on how to introduce children to family members with severe injuries. This family decorated for and celebrated Christmas in the patient's hospital room. She rated her husband's injury severity level as 5 out of 5.

Participant #5 is a 57 year-old, employed Caucasian male who complete high school. He is the father of the husband of Participant # 4. After he was notified that his son was injured, he traveled from within the United States to meet his son at a military treatment facility within the United States. He rated his son's injury severity level as 5 out of 5. This participant filled out the questionnaires as part of Session 1, but left to go home for an unrelated scheduled medical appointment before he could participate in the interview or second BSI-18. The participant was officially withdrawn from the study, but his quantitative data were used in this analysis. The participant, although not involved in the structured interview process, did talk to me about how upsetting it was for him, not

only to see his son with a severe injury, but also to see all the other injured service members who were being treated at the military treatment facility. He became tearful when talking about what he saw at the military treatment facility.

Participant #6 is a 75 year-old, retired Caucasian male who completed the 10th grade. He is the father of an active duty, Army sergeant. After he was notified that his son was injured, he traveled to meet his son at a military treatment facility within the United States. He rated he rated his son's injury severity level as 5 out of 5. This participant reported that this was his son's second injury and that he had been through the process of being notified that his son had been injured once before. He indicated that his son's first injury was less severe because he remained in the Iraq and returned upon the completion of his first tour of duty with Purple Heart.

Participant #7 is a 41 year-old, Caucasian female who completed high school. She is employed, re-married, and is the mother of two young children and one adult son. Her son is an active duty, Army enlisted soldier who was severely injured in Iraq. After she was notified that her son was injured, she traveled to meet him at a military treatment facility within the United States. Her two children remained at her home under the care of her husband. She rated her son's injury severity level as 5 out of 5. This participant reported in conversation that she has prior military service in the Marine Corps.

Participant #8 is a 44 year-old, divorced, African American female who has a college degree, is retired from the Army and is the mother of three. Her son is an active duty, Army sergeant who was severely injured during an altercation unrelated to the current situation in Iraq. After she was notified that her son was injured, she traveled to meet her son at a military treatment facility within the United States. She lives within a

two hour drive of the PRC and is able to live at home while her son is receiving rehabilitation. She rated her son's injury severity level as 5 out of 5.

Participant #9 is a 52 year-old, divorced, Latina mother of three who is employed and completed two years of college. She has two sons who are active duty, Army sergeants; one was severely injured in Iraq. Her daughter is in college and lives at home. After she was notified that her son was injured, she traveled to a military treatment facility in Germany to meet her son, who was later transferred to a military treatment facility in the United States. She rated her son's injury severity level as 5 out of 5.

Participant # 10 is a 44 year-old, married, Caucasian, mother of five who is employed and completed a four-year college degree. She has two pre-school age children, one child in middle school, one child in high school, and one son who was injured in Iraq. The son who was injured in Iraq is the child of her husband's ex-wife and her ex-husband, but because he is estranged from his biological parents, he knows the participant as "mom" and has her listed as his next of kin. After the participant was notified that her son was injured, she traveled to a military treatment facility in Germany to meet her son who was later transferred to a military treatment facility in the United States. Her four other children remained at home under the care of her husband and his sister. She rated her son's injury severity level as 5 out of 5.

Participant #11 is a 49 year-old, divorced, Caucasian, mother of two adult sons. She completed high school and is employed outside the home. Her son is an active duty, Marine who was injured in Iraq by an IED. After she was notified that her son was injured, she traveled to meet her son at a military treatment facility within the United States. She rated her son's injury severity level as 5 out of 5.

Quantitative Measures and Analysis

Demographic Information and Injury Severity. Demographic information and injury severity was collected using a questionnaire developed for this study (Appendix D). Demographic items were similar to those used in previous research (Kolakowsky-Hayner et al., 2001; Serio et al., 1995). Demographic items were reviewed by social workers and psychologists from the PRC at McGuire VAMC in Richmond, Virginia. Perception of injury severity was rated by the family member. Participants were asked to rate the level of severity of the injury on a 5-point scale from 1 (not severe) to 5 (very severe).

Family Needs Questionnaire-Military (FNQ-M). Various needs of family members were assessed using an adapted Family Needs Questionnaire (FNQ-M; Jeffrey S. Kreutzer, PhD, ABPP, personal communication, March 6, 2006). The FNQ was developed to measure family members' perceived needs following the injury of a relative in the acute and post-acute phases after injury (Kreutzer, Serio, & Bergquist, 1994). It includes six discrete scales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care (Kreutzer, 1988). Serio and colleagues (1995) report the FNQ subscales are reliable, with reliability coefficients for the six subscales ranging from .78 to .89. Questions are answered in two parts. First, participants are asked to rate the importance of a listed need using a Likert-type scale rating from 1 to 4 (not important, slightly important, important, very important). Next participants are asked to indicate if that needs was met, partially met, or unmet by circling 'Y' for yes, 'P' for partially met, or 'N' for not met. One military-specific question was added to the questionnaire and spaces were provided to allow

participants to identify any needs that were not addressed in the questionnaire. They were asked to rate each added need as met, partially met, or not met (Appendix E).

Brief Symptom Inventory – 18 (BSI-18). Family member distress will be assessed using the Brief Symptom Inventory-18 (BSI-18; Derogatis, 2001, Appendix F). The BSI-18 consists of 18 response items and contains subscales measuring somatization, depression, anxiety, and a global severity index (GSI; Derogatis, 2001). Psychometric properties for the BSI-18 are good and consistent among various community samples (Derogatis, 2001; Zabora, Jacobsen, Piantadosi, & Owens, 2001; Prelow, Weaver, Swenson, & Bowman, 2005). A score is clinically significant if the T-score of the Global Severity Index (GSI) is greater than or equal to 63 or if T-scores for two or more of the individual domains (somatization, anxiety, and depression) are greater than or equal to 63 (Derogatis, 2001). The BSI-18 is a third generation measure of distress, derived from the Brief Symptom Inventory (BSI; Derogatis, 1992), which was originally derived from the Hopkins Symptom Checklist-90 (SCL-90). The SCL-90 uses 90 items to assess psychological distress, while the BSI and BSI-18 use 53 and 18 items, respectively. The BSI is a well-established and widely used measure with internal consistency reliability range from .71 to .85 (Derogatis, 1993). The BSI-18 has been used in a variety of medical and community settings and is highly correlated with the SCL-90 and BSI (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Jacobsen et al, 2005; Prelow et al., 2005; Recklitis, Parsons, Shih, Mertens, Robinson, & Zeltzer, 2006; Zorba et al., 2001). The short length reduces respondent, administration and scoring burden, making it an ideal measure for use in a medical setting with family members present on the PRC who are busy participating in the patient's therapy schedule and taking care of family and medical

business at multiple locations (home of residence, primary military medical facility, and rehabilitation center). Participants were asked to make a response that best described how much each of the 18 items had distressed or bothered them during the past 7 days, including the day they took the assessment. Participants responded using a Likert-type scale rating from 0 to 4 (not at all, a little bit, moderately, quite a bit, extremely).

Analysis of Quantitative Data. The SPSS 14.0 statistical package was used to examine quantitative data. Descriptive statistics, including means standard deviations, ranges, and frequency distribution were be used to observe the data. Means and standard deviations were calculated for the seven FNQ-M scale ratings (importance and degree to which needs are met). Domains of the FNQ were ordered by rank to assess the relative importance of individual needs and the extent to which individual needs were perceived as met. This analysis strategy has been used by most studies that include the FNQ (Kreutzer et al., 1994; Serio et al., 1995; Kolakowsky-Hayner et al., 2001; Mead et al., 2004). Similar analyses were conducted for demographic information and BSI-18 items.

Qualitative Measures and Analysis

Among counseling psychologists, there is a major movement toward including more qualitative research methods to the "hegemony" of quantitative research methods (Ponterotto, 2005, p.126). From the constructivism-interpretivism paradigm, researchers are less interested in fact-finding and more interested in gaining an understanding the lived experiences of the individual from within their natural environment (Patton, 2002). The shifting of paradigms enhances and diversifies the research that is produced by the counseling psychology profession, allowing for deeper and more detailed insight into human experiences. An ideographic perspective of "understanding the individual as a

unique, complex entity" is used in qualitative inquiry, rather than a nomothetic perspective that focuses on prediction and explanation (Ponterotto, 2005, p.128). From the quantitative or positivism/post-positivism paradigm, the quality of the research is judged according to reliability, validity, and objectivity; from the qualitative or constructivism paradigm, quality is judged by trustworthiness and rigor.

Semi-structured Open-Ended Interview. The purpose of the interview was to investigate the lived experiences of the participants and allow themes from within the sub-cultural context to emerge. The questions were developed by the investigator as a guide to this exploration and were derived from the established body of literature pertaining to family needs following a severe injury and qualitative inquiry (Appendix G).

Observations. During the course of this study the researcher was present on the unit for approximately 30-40 hours per week. This immersed the researcher in the environment and phenomenon under study. Observations and significant events were noted in a personal journal kept by the researcher.

Analysis of Qualitative Data/Interpretation Procedure. Each interview was audio-taped, transcribed and subjected to interpretative phenomenological analysis (IPA; Smith & Osborn, 2003) by the PI and an independent auditor. IPA is a method of qualitative analysis used to explore the details of how study participants are making sense of their personal and social world (Smith & Osborn, 2003). The details of a particular phenomenon are expressed by participants and then interpreted by the investigator. For example, in the present study, one phenomenon under investigation is a family member's *experience* following notification that their loved-one has sustained a serious injury. A

structured interview was used to assist the participant in expressing and organizing these details. Following the interview, the investigator transcribed the verbal exchange and then interpreted the data (as detailed below). A naturalistic design strategy was used; this means there were no predetermined response categories, data collection took place in a real world setting, and the phenomenon was not manipulated, but observed and inquired about by the investigator.

Interpretative Process. Following the structured interview, a transcript of the interview was produced from the audio tapes. Next, the transcript was read 3 times with the left-hand margin being used to annotate what is interesting or significant about what the respondent said. Following the third read, the investigator returned to the beginning of the text and recorded emerging theme titles in the right-hand margin. Themes that organize the responses on a slightly higher level of abstraction and psychological terminology or domains were used at this point. The next step involved connecting the themes. Themes were listed on a sheet of paper, and the investigator looked for connections between them. The next stage involved producing a table of the themes, ordered coherently. The table includes individual or clustered themes with the participant, page, and line numbers of the evidence for (or sources of) each theme that emerged. Once each transcript was analyzed using the interpretative process, a final table of super-ordinate themes for the entire sample population was constructed. A second member of the research team, Michelle Nichols, RN, MSN, the PRC education and research coordinator who has experience using IPA, reviewed the text and interpretative process and procedures of the primary analyst. The next step involved creating narrative accounts of the data presented in the constructed tables. In this step, a detailed

explanation of what the participant said (using verbatim extracts from the transcript) and the investigator's interpretation or account of it was given.

The most significant benefit of using IPA in this study centers on IPA's capacity to investigate human experience within a cultural context (Shaw, 2001). There are many contextual factors that exist and separate the military as a subculture of the greater society (Castro, Adler, & Britt, 2006; Doyle & Peterson, 2005; Figley, 1993; Dirkzwager, Bramsen, Ader, & Van der Ploeg, 2005; Wiens & Boss, 2006). This method allows those differences to emerge naturally. The qualitative portion of this study, using IPA, provides valid, rigorous, and rich narrative information on family member experiences following a war-related polytrauma.

Hypotheses

1. *Health Information* and *Involvement with Care* needs as measured by the FNQ-M will most often be rated as met.

2. *Instrumental Support* and *Professional Support* needs as measured by the FNQ-M will most often be rated as not met.

3. For each scale, the proportion of needs rated as met will exceed the proportion rated as partially met or not met.

Research Questions

4. As measured by the BSI-18, how clinically distressed are family members of polytrauma patients?

5. What are family member opinions of the FNQ-M?

6. What are the participants' perceptions of how the military medical community handled their situation?

7. What do family members know about the condition, treatment, and prognosis of the patient?

8. What problems are family members facing that they do not know how to solve or have been unable to solve?

9. How do family members manage their stress?

10. How has the injury changed or affected their family?

11. What do family members expect to get out their experience at the Polytrauma Rehabilitation Center by the time their family member is discharged?

12. How does having the opportunity to openly express or talk about their needs and experiences affect family members?

13. What are family member perceptions about being interviewed by an investigator who has military and deployment experience?

Chapter IV

Results

A total of 11 participants were included in this study. One individual (Participant # 5) withdrew from the study after Session 1 because he had to return to his home town for a medical appointment unrelated to the study. Four participants who were introduced to the study declined participation prior to consent. Data from the qualitative interview and second administration of the BSI-18 are missing for this participant. Therefore, BSI-18 scores and the qualitative analysis are based on a sample size of 10. Of these participants, one (9%) was African American/Black, one (9%) was Hispanic/Latino, and nine (82%) were European American/White. There were six (54%) mothers, three (27%) fathers, two (18%) wives, and no (0 %) husbands of individuals with polytraumatic injuries. All were present on the unit for the rehabilitation of combat-related polytraumatic injuries with the exception of one European American father, and one African American mother; these participants' children were injured in the United States, sustaining a non-battle related injury (NBI). Participant estimated household income ranged from $13,000 to $80,000 annually. Participant education level ranged from 10 years to 16 years. Participant age ranged from 29 to 75 years of age. Two participants reported they were taking prescription anti-anxiety medication, one at a regularly scheduled interval and one on an as-needed basis, but were not taking it while participating in this study.

Time between family members being notified of the injury and when they were reunited with their injured family member ranged from zero (the same day) to eight days.

Five of the participants were flown to Landstuhl Regional Medical Center (LRMC) in Germany to meet the injured service member, four traveled to Walter Reed Army Medical Center (WRAMC) or the National Naval Medical Center (NNMC), and two (the stateside injuries) met their family member at other facilities (one being another military treatment facility and one being a private non-military hospital). Participants in the study who were flown to Germany WRAMC or NNMC were subsequently flown to Washington, D.C. when their family member was able to be medically evacuated to either WRAMC or NNMC.

Participants completed the interview portion of this study an average of 25.3 days after the injured family member was admitted to the PRC; the range was 7 to 69 days. The interviews took place an average of 69.2 days following the injury; with the range being 30 to 166 days. Time between Sessions 1 and 2 ranged from 0 to 7 days with a mean of 3.3 days. One participant was consented to the study, but then changed her initial travel plans and decided to go home early. However, this participant agreed to continue to participate in the study. At her request, she completed Session 1 in the morning and Session 2 in the afternoon of the same day.

As measured by the FNQ-M, family members rated the importance of their needs in the following order from most important to lease important. *Health Information, Professional Support* and *Military Support* needs were rated equally as most important (respective means = 3.9), followed by Community Support Network (mean = 3.7), Involvement with Care (mean = 3.5), Instrumental Support (mean = 3.0), and Emotional Support needs (mean = 2.8). Of note, all domains with the exception of *Emotional Support* needs were rated as important or very important by the group (n = 11). See

Table 4. Involvement with Care needs were most often rated as met (95.5%) followed by Health Information (88.3%), Community Support Network (67.6%), Professional Support (58.2%) Instrumental Support (40.9%), and Emotional Support (40.9%). See Table 4.

Participant opinions of the FNQ-M were gathered qualitatively (narrative located on page 109). Participants also had the option to indicate on the quantitative survey if a particular question was not applicable (N/A) to their situation. A number of participant responded to two questions as being not applicable. Question #14, "I need to have complete information on drug or alcohol problems and treatment," was rated by five participants (45.5%) as not applicable to them. One of the participants who endorsed this item as not applicable had a family member injured in a motor vehicle accident in the United States. All others who endorsed this item as not applicable had a family member who was injured in Iraq. Question # 36, "I need to be reassured that it is usual to have strong negative feelings about the patient," was rated by six participants (54.5%) as not applicable to them. Every participant who endorsed this item as not applicable had a family member who sustained an injury in Iraq.

As measured by BSI-18 group mean scores, levels of distress of family members of individuals being treated on the PRC were not clinically significant. One participant during Session 1 and one participant during Session 2 had a T-score of 63 or higher on the anxiety domain, but to be clinically distressed, a participant must either have a GSI score greater than or equal to 63 or have a T-score of greater than or equal to 63 on two or more of the remaining three domains (somatization, anxiety, and depression). Thus, no participants at anytime during this study met the criteria for being clinically distressed. Pre-interview and post-interview BSI-18 scores are presented in Table 5. As compared to

published community norms by gender (Derogatis, 2001), during Session 1 the present study population scored in the 42nd percentile for depression, 54th percentile for anxiety, 50th percentile for somatization, and 46th percentile on the Global Severity Index. The Global Severity Index is reported as being "the single best indicator of the respondent's overall emotional adjustment or psychopathologic status" (Derogatis, 2001, p. 6). Following the interview during Session 2 the present study population scored in the 31st percentile for depression, 31st percentile for anxiety, 49th percentile for somatization, and 31st percentile on the Global Severity Index. Although not statistically significant, there is a consistent decrease in the reported level of distress experienced by participants; most noteworthy is a 6-point T-score decrease in the sample's average T-score for anxiety.

A total of ten participants were individually interviewed for the qualitative portion of this study at one time point. Qualitative data are arranged in four sections. This first section details the lived experiences and expectations of the participants involved in this study and is divided into seven subsections: (1) experiences of participants prior to arriving at the Polytrauma Rehabilitation Center; (2) daily experiences of family members on the Polytrauma Rehabilitation Center; (3) family member expectations for the Polytrauma Rehabilitation Center; (4) opinions on the current program of care offered at the Polytrauma Rehabilitation Center; (5) family member perspectives on personal stress management; (6) problems and problem solving among family members; and (7) impact of the injury on the family. Themes that emerged are noted throughout the narratives. Effort was made to keep the narratives as intact as possible. The second section provides feedback on the feasibility of the method of assessment used in this study and participant openness to intervention and is divided into three subsections: (1)

participant opinions of the FNQ-M; (2) impact of the Polytrauma Family Needs Assessment Study on participants; and (3) participant openness for intervention. Please note that "R:" indicates the researcher's comment or question, while "P:" indicates the participant's comment or response. When neither is identified, it indicates that the excerpt represents what the participant said.

Lived Experiences and Expectations

Experiences prior to arriving at the PRC (Phase I). Participants shared what they experienced prior to arriving at the PRC. They retrospectively commented on a range of experiences from the time they received the injury notification phone call to just prior to arriving at the Polytrauma Rehabilitation Center in Richmond.

Forty percent of the participants interviewed reported they had a positive experience and were satisfied with the care they received prior to coming to the PRC. Patients were treated at military treatment facilities in Germany, Washington D.C., Virginia a one non-military hospital in Pennsylvania. Two major themes emerged from their experiences prior to arriving at the PRC: communication of medical information was at times inaccurate and/or vague, and they noted a perceived lack of TBI knowledge in general among individuals treating and working with their family members. Threaded throughout several of the below narratives are themes of confusion and discomfort associated with the large medical treatment team needed for such complex injuries and the very visible teaching of students, interns, and residents that takes place in teaching hospitals; both WRAMC and NNMC are teaching hospitals. Concerns with availability of staff are also present. The first three narratives are from participants who were satisfied with the care they received at WRAMC and NNMC, followed by narratives

from participants who were not satisfied with the care they received at those locations. In the first narrative, although the participant responds that she is satisfied with the care, she notes that early communication could have been better.

> P: I think they've done a great job. Um, especially as far as his care – he's been taken very well care of. To me it has been top-notch medical care. I have no complaints about it at all – any questions I have had, you know, um the doctors and everyone tries to answer them – no problems with that. I think it's been good – so far. I know sometimes – the only thing I had a problem with was when I was initially notified by the Army that he was hurt. But, I know it's because there is a lot going on over in Iraq and Afghanistan, unfortunately a lot of guys are getting hurt and I know it's hard for them to keep up with people, but sometimes I felt like the information may not have flowed as well – like for example, I had no idea until he got to [military treatment facility] – I knew he had the skull fracture – but, they kept saying he had a cut above his right eye and so that's what I was thinking – maybe he just had a fracture up here [pointing] above his right eye. I had no idea about the right side of his head and the brain injury part of it. I called [military treatment facility] and talked to the nurses and doctors there, but, you know, just the flow of information from the time he got wounded until he got to [military treatment facility] was disconnected, if that makes sense – because I was initially told that he had liver lacerations and that was pretty much it. Then, they called and told me he was on the plane to Germany and they say, well he has chest wounds and I was like – ok. But, like I said I didn't even know about the right side of his head and the skull fracture being what it was and the brain injury until I got to [military treatment facility]. I had no idea – that's the only thing that – but, I know because the information was coming from Iraq to Germany to here that it, you know, it wasn't going to be perfect anyway, just because, you know, communications aren't perfect, so that was the only thing that, you know, I really had an issue with because I did not know the full extent of what happened to him until I saw him.
> R: And so um, you understand though, that is was a shock for you to not have all the information when you did see him, but you understand a little bit that's just the nature of how these injuries get evacuated and the different-
> P: Exactly.
> R: Communication and things like that – so maybe they were learning things and passing things on.
> P: And I know communications aren't that great over there, anyway, so – because I worked on a contract deal with Iraq for a year and I just know how, you know, parts of information, would get, you know, just messed up sometimes. So, I understand all that so I'm not angry about it in anyway at all – just, I wish I would have know more so I could have been - 'cause – I didn't have a clue that it was going to lead to us coming here for a while and, you know, just so I could have been more prepared, I think. You know, because of the kids – I feel like

everything has been ad hoc as far as getting the kids taken care of and you know, being away from home this long.
R: Can you think of what specifically they could have done, given what you've been through and now looking back to kind of help you – is there anything they can do – or is that just kind of-
P: I don't know if there is anything they can do though because you don't really know with an injury like he has how long it's gonna take for the rehabilitation process – it's a yes and no kind of thing.
R: Do you think it would have been better for them to prepare you for the worst, or just feed you what they knew as it went along?
P: I wouldn't say the worst, but just had been honest and told me everything up front so-
R: So you feel like they did withhold some information from you early on?
P: Maybe – a little bit – because I would call his nurses when he was still in Germany and they would – I even have a note pad at home where I wrote down everything they said when I was talking to them – and like I said, I didn't really know about the brain injury – no one really
R: So maybe a little bit more information, better communication in those very early days.
P: Exactly, I'd rather have somebody tell me everything upfront versus it being a surprise when, 'cause you know, I really had no idea of the level of damage that he took to his brain, you know what I mean?
R: Right.
P: So, I'd rather know that so – I mean I know it now and I have some – a little bit better picture of how things are gonna be and what his recovery process is going to be like, but at the time, you know, I just felt like I wasn't being told everything that I could have been told. Participant #1, Page 1

P: I've been really, really impressed. I am not sure his wife has been impressed, but I think I've been more impressed because I'm right here watching it happen.
R: You have been with him since [military treatment facility].
P: I have been with him the whole time. I went home for a couple days. But, I feel like the – the military medical community – I feel like they have been right on the ball. I feel like – I made the comment – they ought to be – they got him hurt, so they ought to fix him. But, I don't think as that, I feel like the medical side of the military has taken it very personal they want him well and we want him back to 100% - so I have been real impressed with the medical side of the military. Participant #2, Page 2

P: [Military treatment facility] was wonderful.
R: Ok, can you tell me a little bit about why it was wonderful?
P: Um, I guess I never really had to ask questions. The information was there, it was brought up before questions were asked and if I did have a question, they

were always there to answer. I never – they never told me to wait – that they had to look it up on the computer – they had an answer. I understand, it's easier on the computers, um, but it's just nice to know within a certain amount of time – instead of waiting forever to get an answer. Like I say, I've not run into it a whole lot here, because [my son] does not require the medical attention here that he did there.
R: So, at [military treatment facility], you felt any of the medical doctors were available whenever you needed them?
P: Oh, yah – there always somebody there to get a hold of. Participant #11, Page 1

P: [Military treatment facility] in my point sucks. I've heard they're the best medical care, but as far as my husband's situation, they have a long ways to come. If you're an amputee, they're great. But as far as for TBI, they need a whole lot of training.
R: Can you give me more specific examples of what your experience was like up there?
P: Well, the hospital is filthy. The rooms are absolutely ridiculous – I mean they're filthy. Their whole – I know they are going to be tearing down, but yeah – you're still taking care of soldiers – and us constantly hearing that "we're short staff" well, you know what? That's not the family's problem that you're short staff. You're still here to take care of the soldier – whoever it is. And because you're on a four-day weekend, I don't know how many times I've heard that – well that's not my problem, he's still not – not sick when it's a four day weekend. You need to deal with it and go on if you can – but, the civilian mix and the military mix is not a good mix. We had a lot more issues with civilian nurses dealing with [my husband] than we did the military nurses. Because their care, I don't know why, but they – I had one that actually tied [my husband] down.
R: Really?
P: Yes. You know, because he was tired of dealing with [my husband].
R: Ok, that was a civilian nurse?
P: Yes, it was. And their nursing staff, I think needs to be more up to date on TBI patients. There needs to be a lot more training. They have PICC line nurses and they have special nurses, they need to get nurses who are specifically trained on TBI. That's my opinion. Because TBI patients are very unique that each one is different, but it is totally different. I mean, [military treatment facility], as far as caring for amputees, that's been around for a while – it's not as complex and complicated as traumatic brain injuries.
R: Can you give me one example that makes you feel like they need more training?
P: Just like I said with the civilian nurse. [My husband] was constantly wanting to get up and [the nurse] got tired of having to deal with him, so his way of dealing with it was, [my husband] was already in restraints and restraints have to be ordered and then he took a sheet and tied [my husband] down and it was completely across his body and the way [my husband] moves around in his sleep – he could have actually suffocated. And his theory was that he was tired of

messing with [my husband] having to go back in and make [my husband] stay in bed – well, for a nurse, that's your job. I don't know if he just didn't understand where a TBI patient is – their brain is not really functioning and they can't really control that. So, and it's not just – even some of the doctors don't understand. I can't tell if it's the military backing or the civilian side of it. But, there was no communication there at [military treatment facility]. You know they're good for acute care, but as far as with [my husband] with the TBI, the left didn't know what the right was doing. So, you'd talk to one doctor and then the next doctor would come in for the specialty and then the main team would come in and tell you something else. So, it was constantly back and fourth and I never got a straight answer.

R: So, better communication among the team.

P: And the nurses – between the teams and the nurses. Because the nurses would be told one thing and not tell the family member – and the family member needs to know what is going on with their care. And the other thing is here [McGuire VAMC PRC] they come in and actually talk to the patient and at [military treatment facility], they don't - they talk around them. And I talked to several different people who feel the same way on that. Yah, some of the patients they can't talk to, but the ones who are cognitive enough to understand or feel like they might understand – they should talk to them because the care is about them not about the family member.

R: So it sounds like you would change the communication among the staff and you would also change how they would interact with the patient and that sounds to me like in general they need more education on TBI and then how to communicate those issues to family members. Those would be things you would change.

P: Right. Right. There's a communication problem between Iraq and between [military treatment facility] and between each unit. They've got to figure out a better communication – I honestly think – they have those Hero Books – they're pretty helpful, but they should have – when we got to [military treatment facility] – I was fortunate enough that my husband's Colonel's wife lived close enough that she could go through the steps with me – but this war has been going on for several years now, so this is not new stuff. They should have everything wrote down – and there are always exceptions – but somebody should be able to meet you, hand you a book and say, ok, read over this, if you have any questions, we will meet back up with you in a day or two so that we can answer all of your questions instead of just shoving you in – your in the hospital room and this one coming in and their handing you their card and you have another one coming in – I mean you're not ready to deal with all of that, but I think if they have everything wrote down – a book of some sort. There's procedures for all of this – it's not like it's new stuff.

R: Right, so all the way from the unit commander – the rear detachment commander or maybe the family support group leader – family readiness group leader could be more trained on how to walk people step-by-step through the process…

P: Right. Right. Of course each situation is different, but for the most part, they know when they get to [military treatment facility], you're gonna have to do finance, you're gonna have to do this, you're gonna have to do that. It needs to be in writing because you forget some of the stuff and some of the services don't apply to some of the family members. But, for someone who has military background (family) it's not as big of an issue, but then you've got the single soldiers with family members that have no military background. They're hanging out here wondering, "What the hell do I do."
R: Now, do you feel that having one person assigned to your case that you meet when you get phone call all the way through would be helpful or would it be too much?
P: No, I think actually that would be good – because then they've got it from [start] to end, instead of ok, this person calls you – you get to [military treatment facility] – there's somebody else – and then there's somebody else – and somebody else – and you fall through the cracks. Participant #4, Page 1

P: It stinks.
R: Ok, can you tell me a little bit more about it?
P: There's no communication between, I don't think personally my opinion is, I don't think at [military treatment facility], here is a totally different story, so let me…
R: Sure, so for what you are going to say is about your experiences before you came to the PRC.
P: Right. There is not enough communication. There is not enough care for the family – "let me explain to you why we have to do this", "let me explain to you why [your son] is being taken down for this." Um, "I understand your concerns" there's just no communication there. And that's rough on a family. Uh, when you ask for a doctor because say [my son] is restless, he's aggravated, he's not getting any sleep, then you say, you know, "Why hasn't he been given his Ativan?" And it's six-thirty at night and she [the nurse] says, "Oh, I'll be in there a few minutes." And by 7:30, I'm standing out in [my son]'s doorway saying, "Ativan!" And she says, "Oh, yah, I was supposed to give it to you half an hour ago." Unacceptable I'm not [my son]'s doctor. I don't hand out medicine. Get with the program. You are the professional. This is what you are being paid for – my son is a patient of many, one of many. But, he deserves that individual care too. So, it was a horrible experience at the [military treatment facility]; horrible. And I went and talked to the admiral there who is in charge of the hospital – the Chief of Staff- actually is who I talked to. And I went though all of this with him and that next day, everything just started to get better. People were paying attention and talking to us and taking care of things. Well it should have never had to come down like that.
R: Sure.
P: I'm in the military – or used to be, I know there's a chain of command and had I had one or two problems, I would have never went to him. But, it was one or two or three or four every single day. And if it had been well [my son]'s been for

three days – and "-oops now we have a problem." These things happen, but when my son first got on the 5th floor, they had a corpsmen from the psych ward, one each hour, come in to sit with my son who was strapped to the bed because he kept trying to pull things out and I wanted him strapped to the bed because these corpsmen weren't stopping him from trying to pull IV lines out , they didn't keep him on the side of his head so he had to have another surgery which would have not been needed had they kept him on the right side of his head in ICU – they didn't know how to suction his throat, he was losing his breath when he was coughing – they didn't know how to take his temperature, I had to – so that night that first night, again, I go out of the room, "I don't think you all understand, this is not my job, although I would do it if I knew how. I don't and you need to get somebody in here who is experienced for my son. And then somebody experienced came in. But, you shouldn't have to do that.
R: So, what's a corpsman? A lower enlisted?
P: Oh, yah, probably a first enlisted – and they have to get experience, I understand – everybody needs experience, but not with somebody who is coming directly up from ICU who is trying to tear all their stuff out. And they're gonna sit there with a TV two feet in front of them?
R: So you didn't have any medical background coming into this experience, but this is what you've learned and just your sense as mother on what needed to be done and then when you brought it up, it actually was done.
P: Right. It was taken care of. 'Cause everything that I told them that I'm telling you, they said, "Unacceptable, should have never happened." Finally, somebody can validate my feelings. Participant #7, Page 1

P: Before he came here, the first military medical staff – I was not, um, comfortable with their, I don't know the correct term, but to me it's the bedside manner that they had at the military hospital. So, with that, I definitely had to be there to make sure that he was taken care of appropriately.
R: And what military treatment facility?
P: Portsmith Naval Hospital – basically, because of [my son]'s condition, they felt that um that he was not going to improve and because they felt that he was not going to improve, I felt that his care was – the way they felt about him – if he's not going to improve then we really did not need to take care of him, not necessarily take care of him, but they didn't think – I thought that they didn't think that his condition warranted their time.
R: Right. Right. Kind of, if he's not going to return to duty-
P: If he is not going to return to duty basically he – we were told um and - these were the words of the neurologist that – "He is no good for the service, he was not going to recover from this, um, send him to a nursing home and that's the best thing we can do for him." And they came in with their morning check and basically that is what their attitude was. If he's not doing anything why even come and bother doing the morning routine that they do with each patient. I felt they felt they could just bypass his room because he not going to recover from his incident. And that's how I felt about the medical staff there. Participant #8, Page 1

P: In general, I feel like [my son]'s entire case was handled poorly. I just do. It's just because of all the things I have been through and being able to reflect and being able to say – this is what should have happened. You know? And maybe not – I don't know because I didn't live the other side of the coin so to speak. It's hard. I think the reason it seems so poor is because it's a teaching facility – and not to say that there shouldn't be teaching facilities, um – it's just very had on the families. You know, as long as you're in the Army and you're active and you're going through things maybe personal and that's all fine and dandy, but this is detrimental – this is like, your family is involved – your mother and father – your brothers and your sister. Because like in [my son]'s case, you can't speak for yourself and you can't make decisions for yourself and you're thrown into this whirlwind that everyone is used to and your thinking what the heck is going on here. Participant #9, Page 13

At Water Reed there're thousands of doctors and thousands of interns and residents and mix-mashing and everything coming and going. Participant #2, Page 2

[At military treatment facility], there's not much access to doctors – to me that was a confusing mess there because you would see doctors going around in groups around the floor [presumably medical students on rounds with an attending] and you'd think, ok the doctors are coming and they're going to stop outside your room and then that's when you can grab them and talk to them. And you'll be in there from seven in the morning until one in the afternoon, thinking they're gonna come anytime and you don't want to leave because you'll miss them, you see. And then that group comes and stands outside your door - well, they're not your doctors at all, it's not your team of doctors. So then there's team this and team this and team this and how do you differentiate? And we were never introduced to the team and that's confusing and you don't feel like you have access to them – and other people would say, all you have to do is call up and get an appointment with them – you can do that. Well, you ask a nurse that and it doesn't happen like that. You can't get an appointment to talk to that doctor – so, the doctors are out of reach there. To get to talk to a doctor is heck. And I was there one day early, early, to get to talk to a doctor and I was there all day – 2 o'clock, still hadn't seen a doctor, and I went and talked to the nurse and their ICU was good, but by the time we got to the 5th floor, surgical area, it was terrible. I'd been in there three days, because at that point I was doing 4 days at home and 3 days there with him and 4 and 3 and 4 and 3. For 3 days I'd been there and I hadn't even seen the nurse who was his nurse in his room – and that irritates me. I mean, a corpsmen, a 20 year old corpsmen who's the equivalent of an LPN was who took care of him from morning until night and they did 12-hour shifts and there were two of them in a 24-hour period. And they were good kids and he related to them because they were young like him, but they're not nurses

and the nurses were nowhere to be found or they were doing their own thing and because there were people who were more severe than him, you know, I tried to give them the benefit of the doubt, but they could have at least come in and introduced themselves. Finally when I needed a nurse that third day, I said, I would like to meet with a doctor, I've been here 3 days and haven't seen a doctor, don't know who the nurse is for the day. Could you point me in the direction of my nurse so I could talk to her and they did and I said, I would really like to talk with the doctor today? We have some things we need to figure out and we're at a crossroads here and I need to discuss these things with a doctor. And they said well, we're gonna page somebody and then an hour later, still no doctor. And then they tell me, well, your doctor's not in today, it's gonna be an on-call doctor. Ok, so an on-call – long story – so another hour goes by, [my son] who can hardly get out of bed at this point and when he does he's supposed to get his cap on – and he's frustrated too – because he would like to see a doctor because we have some decisions to make and we'd like to consult a doctor before we can make decision about where he's going next, if we were coming here or where we were going and we needed a doctor's advice and we needed to know things. And we needed to make that decision over that three-day span that I was there because it all was gonna get rolling.
R: Sure.
P: So, anyway, he gets frustrated, he sits up in the bed, get's out of the bed and he's supposed to have his thing [helmet] on, you know, he's just like two days into walking at this point, so he stands up and we just think he's going to try to go to the bathroom by himself, because he's supposed to be escorted. He gets up, walks passed the bathroom, walks out into the hallway, and, if you know how out of it he was, he sees a man and thinks that's the doctor because he's wearing a lab coat, but it's actually the male head nurse, and he goes up to him and say, and you know he can't talk yet, and he said, "What's up?" [Laughing] And the guy says, "Hi there, nice to see you, Mr. [name removed], nice to see you, I met you when you first came in, enjoy your walk with your mom." I said, "Oh, no, no, no, that's not what he's out here for." I said, "He's kind of frustrated because we've wanted to see a doctor all day long and it's now nearly 5 o'clock and we haven't seen a doctor yet and a doctor was paged maybe, at 2 o'clock, so do you think you could get a doctor for us and [my son] said, "Right on!" He couldn't say it, but he knew I said it right. Participant #10, Page 7

P: I had to ask for them. I had to, I guess initially, I was just kind of under the impression that I would be told by someone or at least by a member of the team what [my son]'s status was, but I kept getting it in bits and pieces. I think I kind of told you a little bit about that last time – there were so many categories of physicians and interns that I didn't realize until further on that I was the one who had to put all the specialties together to make sense of [my son]'s overall progress. Where something were important to one, they weren't that important to another – so people had different opinions and stated different things, so finally I said, I need one person I can go to – I need a "go to" man that I can ask anything

> from – so that I am not addressing something to you that is not under your category. And so eventually, but it took a while, first of all to realize that, second of all to get it, but once I requested it then I was given someone. But, that went by the wayside once that particular physician was on to another part of the hospital. So because it's a teaching facility as far as [military treatment facility] or even [military treatment facility] was a month – so I can't really – I only had one experience there that was a turmoil and was the reason I wound up at [military treatment facility] and that's how I look at that – and [military treatment facility] was my longest stay. And that's where I finally realized, wow – if I'm talking to one set of people about a certain thing, they might not be the person I need to address and they'll tell me that, but then I have to figure out, well, who is that? You know, there should always be one central person – overall – who can give me an answer or find out and get back to me.
> Participant #9, Page 1

Daily experiences of family members of patients on the PRC (Phase II). Overall, participants reported spending most of the day on the PRC and were actively involved in the patient's rehabilitation program. Three participants, all with prior military experience, felt they needed to be with the patient more for their need to be there rather than the patient's need for them to be there. Participants who have children at home actively managed the patient's daily schedule and affairs, while being actively involved in daily parenting responsibilities of young children from a distance. The following excerpts offer insight into the daily lived experiences of family members.

> R: If I followed you through a typical day of what your life has been like since you were notified that [your family member] was injured, what would I see you doing?
> P: Get up. Get ready – come to the hospital and hang out here. I go to his therapies with him. Sometimes I'll take a break and step outside and go call family or just sit outside by myself for a little bit, just to step outside the hospital walls. And, that's basically about it to be honest with you.
> R: So hanging out here, what does that involve?
> P: Like I said, I'll go to his therapies with him sometimes – or I'll just hang out, like right now, he's in speech therapy and usually I don't go in there, so I'll sit [in his room] and watch TV or read a book or something or go check my email. You know, things like that – go outside, go get a drink, you know try to walk around. I'm kind of an antsy person anyway, so I get tired of sitting around – so I have to just get up and walk around, so that's been kind of hard – just to sit here sometimes and not really have a lot of stimulation or things to keep me busy.

R: Right. Ok. Participant # 1, Page 1

P: My typical day is that I try to get here early for him and I try to be here all day long for him. And I stay until I feel like he is settled for the night. And then I go [back to the local hotel] and I try to sleep a little bit and so my typical day is – just you know there's day when I do nothing but sit on the - when we first got here and he was non-mobile, then I would just sit in the chair ready to jump at any minute and be there. Now that he is mobile, then I am less needed. And that's been the plan all along – the more mobile he gets the less needed I – so I can go home. My day starts, if possible, at 7am and goes until 9pm, which is probably why I have a cold.
R: So most of your time is spent here and then in the evenings you go back to a hotel and sleep intermittently…
P: And sleep very intermittently. And I get there, and the other downfall is that all of my family all lives in the West, so we're on a two hour time zone change – so I call them when I get to the room and then I spend two hours catching everybody up on what's going on in my world, so it's 11 – 11:30 – 12:00 before you get to sleep and we're up at 5:30. So, that's a very typical day and if I am lucky, he'll take a nap and I can take one with him. So, for me that's a typical day. I don't know if I'm a typical mom. Participant #2, Page 1

P: Talking to the doctors and the nurses… dealing with the doctors and the nurses and talking with the therapists and showing them what I did before I came here – to help them better understand what – some of the things that I have already accomplished. I knew that I was not going to get him where he is now by myself. But, I did what I thought was the right things to do – and some of the stuff would be showing him flash cards, picking his memory a little bit, working on the different things – spending time with him – letting him know that I am here. I don't actually have to be right beside him like I was when I first got here. I don't have to be Johnny on the Spot right with him - where when we first got here, I was here at 8 o'clock in the morning and here 'til 8:30 at night and then I would go home or back to the hotel and decompress – watching TV, drinking a cup of coffee, you know, whatever. The little bit of time that has passed by, I started coming in a little later, leaving maybe a little bit earlier. Taking an hour when I would disappear - maybe just going down to the mall or something, but I was in the building, but yet, not here [physically present on the unit]. And as long as he had a sense that I was around – I think that made a difference. Because I did hear that I was "missing in action" in the words of one of the nurses at the station – "your son's looking for you." I'd been gone for probably over an hour and he did not know where I was at, so, but he knew I was around.
R: So, in the beginning, you did very active things with him, in terms of helping with his memory and now it's more like a distant support kind of thing – he knows you're here if he needs you, but you are not as actively involved.

P: Right, but I am also correcting and staying in touch with the all the therapists. When [the occupational therapist; OT] finished up all his stuff the other day, [my son] would go away and then I would take 2-3 minutes of [the OT]'s time to find out what happened in session and what I can do to help support what was learned in that session to continue reinforcing that. Basically, like a building block thing. You have to start with a good foundation and then build it and then – I just needed to find out what things I needed to do to help support whatever was just done. That included with [speech] and I just talked with [physical therapy] on their way up through from down at physical therapy to make sure that I get any or all plans or exercise or something like that he's going to need to work on a deficiency that they find in his left knee and leg and exercises that we can work on – where he's going to - I can do them in a way that out of this setting – that will get the job done, but not look like he's doing it. I'm a [Navy] chief, I'm sneaky. That's what I do.
R: So, it sounds like you are very active member of the team here -
P: I try to be –
R: And you feel very included that the therapists are giving you the information that you need to help you help [your son].
P: And if I am not getting it – I ask. Sometimes – I might ask the same question that they are about to tell me information about and I've been told, "Well, that's kinda, weird because I was just getting ready to tell you about that." You know.
R: So, you are being very proactive – that's great. Participant 3, Page 1

P: Running around with my head cut off [laughing]. There's been a lot backwards and forth since his injury. There's been a lot of crap that I've had to go through as far as with the military aspect of it.
R: Can you define "crap" for me?
P: Well, just like now, it's a backwards and forth thing with trying to get your stuff situated around with the kids. That's been a big thing.
R: Ok. Participant #4, Page 1

P: Just concentrating with…on him. I have been with him all the time, you know. You know it's not really bothered me much mentally or physically – just glad I could be with him. Participant # 6, Page 1

R: What's that been like on a daily basis?
P: Hard, like I said, I got the two little girls at home and my husband and I've got [my son] here, so I've got heart strings in both, you know one eight and a half hours away and the one right here can't communicate with me. Can't tell me what's hurting, what's wrong, how you're feeling, what can I help, what can I do. So, just a mother's nightmare. And I buried one child. So, I thought that was the hardest thing I'd have to go through in life and it was not.
R: What you are going through with [your son]-

P: Is much harder.
R: Ok.
P: It's eased up a bit yesterday and today, but the first 4 weeks were torture.
Participant # 7, Page 1

P: When I get up in the morning, I'm just waiting for my ride to come here. And when I come here, the first thing I am thinking of is that I need to have that first cup of coffee, you know? But, I come in, and my first intention is to see [my son] and make sure – I mean if he's, like if I notice that he moving –there's movement and he's a little more aware, I stay and I talk to him and ask him how his day's going. I'll look at his face, does he need to clean his face or maybe get a shave. At the very end of my stay at [military treatment facility] I started putting cologne on him because I could see that he was like – oooh! That smells pretty good and I'm thinking, this is who he is – he's a guy who gets up in the morning, he shaves and puts on – he smells like a million bucks before he walks out the door. And that's who he is and I want him to have the semblance of normalcy. T-shirts. I started putting t-shirts on him at [military treatment facility] because that makes him feel like a person as opposed to this gown they're just draping over you or sometimes just barely hanging on you. The nurse thought that was pretty cool when we asked if we could put t-shirts on him and she said, absolutely. He was at a stage – all those people got so close to him because he was at a stage, he's been there so long – he just became routine and they just expected to see [my son]. When I left they were all lined up to say goodbye.
R: You can get attached.
P: They got attached, yah. But, getting back to my normal day, I would just get up and come here – I would – once someone is in the room working with him, I feel like I can run get that cup of coffee and come back. And if I see him, if I see that he is resting, I'll say to myself, this is when you can go to the computer and send that email or make that phone call or whatever you need to do. They put him in a chair and I feel like – we need to take a spin.
R: That was really neat that I could witness that yesterday [being up in a chair for the first time] -you guys being able to go off by yourselves and move around together.
P: And we'll stop in the hall way and I'll tell him – do you hear that? Do you hear the people talking downstairs? Some of them are looking up here now – and I'll tell him there is a pharmacy below us and that is why you hear more noise here. I'll say, "Do you feel at all that it's bright outside – that there's a sun outside?" Because I don't know that [my son] can see, so I speak to him in the terms that he cannot see and I describe things to him. And that's just for him because if you're still able to think and process thought then you would say, oh, so it's sunny outside, you know. And I said, there's a big open window where the sun comes in and sometimes it gets really hot down there. And he knows what I'm talking about and can connect. And so, those things are really important, but like whenever there is involvement, that's really cool to me. Like yesterday when with the dogs – that was just so cute. He really reacted to that dog. Participant # 9, Page 11

P: Um, when I'm not here – sleeping. Other than that, when I'm here, I'm doing therapy, sitting with [my son], very dull and boring.
R: Dull and boring.
P: I spend a lot of time with [my son] and other than that, sleeping.
R: Sleeping. Ok. How early are you here in the morning and then what time do you leave?
P: Usually, I try to get here about 7 (am) – before he starts his breakfast and I'm usually here, at least, all day. And if it's a night that I'm spending the night, then I am here all day and all night and all day the next day.
R: Ok, is that pretty much how it was before you came here, as well?
P: Yes.
R: Pretty much with him all the time.
P: Yup. Participant # 11, Page 1

All three participants who have prior military experience expressed a need to be present on the PRC for their own need and that this need changes as the patient's condition improves.

P: And he would say mom-well he's already told me four times, "Go home, mom. I'm ok." But, I'm like, "But I want to be here for you [name removed]." - "I'm ok, mom" – "I don't care if you're ok, you know, I'm your mom, I need to be here." But, he doesn't need me. Participant # 7, Page 7

P: My typical day, um, basically, just coming up to see my son. Get up, get dressed, try to do some chores around the house now. I am trying to get back in the rhythm from before [my son's injury] because he's progressing so much now, so I'm a little bit more at ease. So, but, there is still a part of me that has to visit him every day.
R: So you want to visit him everyday – you *want* to – and then there is a part of you that does not *need* to because of his changes.
P: Let me see, it's part of me saying that I need to see him, but I don't think it is necessary for me to see him everyday, but it is just part of me that wants to see him everyday.
R: And why was it necessary before?
P: Because he was in a critical state before – touch and go. And, um, I just didn't feel comfortable leaving him in the hospital – I just didn't feel comfortable being away.
R: What are some of the reasons why you were not comfortable?

P: Partly, it's because of my past experience dealing with the military medical staff and also that um I felt there was a need for me to be there. I just have to be there.
R: You just have to be there
P: I just have to be there.
R: Ok. Participant # 8, Page 1

P: Talking to the doctors and the nurses. Seeing how he is doing – sitting down with him – taking. Even when he was intubated with a tube at the other facility, we would be with him for an hour or so and we'd take a break for 15 minutes or whatever, outside – had to go get my breathing treatment in [smoking a cigarette]. And come back up and sit with him some more and it wasn't so much that – he was more medically attended then – and it was more – I wasn't there for him, but for me. Does that make any sense to you?
R: It does make sense to me.
P: Ah…[trying to search for words to clarify]
R: There because you needed to see that he was ok?
P: Yah. Participant # 3, Page 1

Two mothers with small children at home share some of the challenges they face.

P: I wake up at 6:30 in the morning with a telephone call from home. My husband's getting home from work at 6:30 in the morning and he calls me and I get to hear about if the kids are all up for school or else if he doesn't call me then I'm calling there at 6:30 to make sure everybody's up and at 'em and ready to go to school. All the kids got their homework done last night, notes are signed, all those things are in order-
R: You have 4 kids at home and in -
P: School, two in elementary, one in middle school and one in high school.
R: Wow.
P: So I'm trying to run [my] home from here too. So I make sure everybody's in order, everybody's up, showering, getting dressed, and he's on top of everything. And [my husband]'s sister is helping stay there with the kids too - to try to help run things. Yea, but she's not real – our standards are different, but I'm real thankful to have her helping. We're not the same people, but anyway – that's what I start with. And then some days there're crises going on, um for instance ok so, I get to hear that [my daughter] asked if she could go after school to do such and such and she was told no and then we have a discussion that she was told no last night by me, but she's trying to play both of us because we're not together and she was grounded last night because she went to practice and made her own travel arrangements home rather than doing the travel arrangements that were made for her and those travel arrangements were going to bring her home four hours later, so we had a whole mess yesterday evening with her because in the midst of all this stuff at Fort Lee [a senator wanted to visit the patient and they had to quickly travel to Fort Lee to get a uniform for him to wear during the visit]

I'm getting telephone calls from home saying [my daughter] didn't come home from school – where is [my daughter] does anyone know where she's at? And I said she had track practice, she was supposed to ride home with [name removed] and [name removed]'s mother and so then I call [name removed]'s house and talk to [name removed]'s dad and [name removed] didn't go to school because she's sick. So I try to call another girl's cell phone and they're not answering – which is infuriating me because I know they're not answering because they know it's my cell phone calling. So, it was hours of this – and I had a 13 year-old daughter crying last night because I grounded her and me trying to explain to her that you made poor decisions here and you can't change the things that are in place and if you do, you have to consult with an adult and you took it upon yourself to make these decisions and there are consequences to your actions and I'm glad that you think you learned something from this, but I'm going to make sure that you do because you're grounded for three days. And of course that tore her world upside down because [using daughter's voice and tone] she's not going to get to see her friends for three days and she's going away on spring break next and she doesn't even want to go on spring break – she doesn't want to come to Virginia – everybody else takes their families to a beach you can swim at, not a beach that's going to be cold. And I said, well, you have an educational family who wants to take you to DC to see things of interest. So, this is what my day is like [bursts out in laughter].
R: Wow. Those are very real crises that you have to manage.
P: They are.
R: And so you are very actively parenting your children at your home which is-
P: 600 miles away
R: 600 miles away and you are also very actively involved in [your son]'s situation here.
P: Trying to do it all.
R: Trying to do it all.
P: Yah, so, last night I was up until late talking to my daughter on the phone, then I had to talk to my husband, then I had to talk to aunt [name removed] so she could know what was going on, so it's a lot of phone calling all around to make we're all on the same page. The first two weeks, the three of us adults did not communicate well and our children were getting away with murder because we were not communicating well and now we've learned that no matter what we say or do, we have to communicate it to all three and make sure our circle is like this [interlocking fingers] and everybody knows what's going on - so we were weak at the beginning and now we've learned.
R: You've learned.
P: So, it's one crises after another- I went like 5 days with none and said, yes – this is finally leveling off and things are going smooth and then yesterday the dam broke again. But, it's alright we're getting there. And I keep saying, do you want me to come back? You tell me when it's time – when you can't handle it anymore at home and I'll turn around and come back. And he'll say, no I think you need to be there with [our son] and I said if you change your mind, let me

know – whatever you guys want. I want to please everyone, but I can only essentially be one place at one time – there's only so much of me to go around.
R: Right. It sounds like you are just doing amazingly –
P: I'm trying, but last night I was on melt-down level – it was a rough day yesterday [bursts out laughing], but I'm better today.
R: Good. Good.
P: And [my son] was in a mood yesterday too and of course that affects my mood when he's in a mood, so we just play off of each other. I feel like I need to keep up, so he will keep up. You know.
R: Alright. Ok.
P: So, it's chaos. But, it's chaos when I'm home too, you know, because when you have four kids life's just – you know, you don't plan too far ahead because life changes on a daily basis and I'm a teacher by nature, so I am used to following things by a lesson plan and having that kind of organization in my life, but as I've had four children, I've understood that you just throw it all out the window and it doesn't really matter what you plan – you just have to be willing to be flexible and go with the flow.
R: Flexible….I had a thought I was going to ask you about, but it left.
P: That's probably way more than you want to know [laughing].
R: No. No. It is absolutely fine – a lot of stuff going here and at home.
P: I come here – do my thing in here- and then leave at 8 o'clock at night.
R: And what does your "thing" here look like?
P: Well, I'm trying to go to some of his therapies with him, at first I went to all of them – except the KT [kinesiotherapy] because he didn't want me to go to that one – so I respect whatever he wants, you don't want me to go – he said it's just guys exercising –they wouldn't be comfortable with you in there because the other guys are in there. I said, no probably. But, you know, I have been to all of his therapies, so I know what they all looks like and what he is getting each day – I don't go everyday to everything, except speech. I do try to go to speech everyday because when we leave here, he'll have speech therapy at the [city name removed] VA hospital of which I am unfamiliar - I don't know how qualified they are or what their speech department is like. But, I know that because I have an education background, things he's doing are all things that are perfectly within my realm of teaching preschool and elementary ed. that I've done and he's basically going to be re-taught everything and I'm able to do all of that. So, I'm just watching to see how she [the speech language pathologist] progresses it, how she formats it and things like that and making notes to myself so that when we leave here I'll be able to do my own therapy with him to supplement whatever is going on at the VA hospital.
R: That' great.
P: So that is the one I try to go to everyday and the others – I touch base – go a day here, a day there, what have you. If I'm not there, then I'm helping clean and tidy his room – motherly stuff that he doesn't think I ought to do, but just can't help it because you're at home, you're cleaning and picking up and it just – you seem lost if you're not cleaning and picking up and throwing in a load of laundry – so I'll do that kind of stuff and I'm also trying to – anybody who sends him

something, I am also trying to write the thank you notes for that and take care of all those communications. Earlier on, nearly everyday, I was sending out an update to everybody of what was going on and now that our crises are gone for the most part and everything's calmed down – we're not in a life or death situation anymore – now it's leveled out to where I'm communicating home with everyone, one a week, maybe twice. You know, all his military guys, his sergeants, prior chain [of command] at home and various people. So, I have a huge list of names that I send to and try to send them an update.
R: Sounds like you are staying very active in all the different communities you all are involved in.
P: Trying to keep all of them posted on his recovery and things. So, I've been trying to [inaudible] and I've been remiss this week and people contact my husband and say, she hasn't sent out a letter this week, are you gonna send one out? So I have pressure from him to do my normal duties of sending that out and be the secretary, so I'm working on that today. I've already written five or six thank you notes this morning and now I'm going to go back and write the long one later this afternoon. We eat meals together and he talks with me whenever he's not in therapy. He talks. And even though he's a big boy and he could probably be without me here, on the other hand, I think he needs me here because he will share with me things he won't share with anybody else.
Participant #10, Page 1

I function – I have managed to tell my husband what bills to pay – I've had to make a couple phone calls to say, look, this where I'm at and this what I'm doing and if you bother me again, I'll just cancel my account – I just don't care about these things right now…Hard, like I said, I got the two little girls at home and my husband and I've got [my son] here, so I've got heart strings in both, you know one family eight and a half hours away and the one right here can't communicate with me. Can't tell me what's hurting, what's wrong, how you're feeling, what can I help, what can I do. So, just a mother's nightmare. And I buried one child. So, I thought that was the hardest thing I'd have to go through in life and it was not….My main concern is [my son] and [his wife] and them being taken care of. And that's why I'm still here. You know, his dad went home probably two or three weeks ago and he comes up on the weekends, but [my son's wife] feels more comfortable around me. I'm not a very judgmental person – I try to be there for her and take care of her – I did her taxes for her, so she could go ahead and get them filed. And we took care of a lot while I was here and that was one of the other main reason – 'cause she was so dependent on [my son] and she couldn't be. So she needed to depend on somebody, thus here I am. So, I feel like we've gotten a lot of the major things taken care of and I've saved her paper work, organized her room – got her room clean and now I feel like she'll be ok until I get back. Participant #7, Pages 6 and 3

Family member expectations. Participants expect to gain functional outcomes in the patient and education and training for themselves while on the PRC.

> P: Um, well it is obvious he has made great progress, so that's a big thing. That um – 'cause he got to a point at [military treatment facility] where he got really upset – and he was like, I just really want to go home. And I said to him, I said, no this will be good for you to come here and go through the whole rehab process 'cause I said, you can't go home right now. He was still at that point, having a hard time getting up and walking around and I said you can't go home because I basically could not leave you at home alone to go to the store or something like that, so I think he has made wonderful progress since he's been here. And that was kind of my big expectation is that he would do better once he got here and he has.
> R: So, progress in terms of -
> P: His rehabilitation –
> R: You mentioned getting up -
> P: Walking around and -
> R: Doing things for himself –
> P: Right. Right. Participant # 1, Page 5

> P: I hope that he is walking and using the bathroom like a normal person. That's the ultimate goal and from everything I have heard, I expect that to happen. And because everybody keeps – and because everybody keeps everybody's spirits up and keeps the positive thinking - I truly believe it will happen. I think that's a big thing is keeping the psychological side, as well as, the physical side – keeping them believing that.
> R: The hope and the motivation helps you feel that is actually possible.
> P: That is what they keep telling us and I don't think they would tell us it is possible, if it wasn't.
> R: Right. So, walking and independent with using that bathroom - those are your two big goals.
> P: Yup. Mentally, I feel like the bump on his head that cause his confusion and his brain injury – I think he is very fortunate. I have seen worse here and I think he is very fortunate and I don't think that's going to be a big – I see little things that weren't him before – his anger, he is quicker to jump and snarl at people. But, I see that – he'll learn to control that. So, he'll be ok. That's my goal and that's his goal. Participant #2, Page 4

> P: I think I've gotten everything that I need.
> R: What are some of those things?
> P: Getting him back to full function – where I can trust him to go somewhere by himself – which I tested in short and long durations since I have been here – which is – that might have been one thing, I would take him down to go outside and get some air and I would walk back in, just for a minute or two – you know,

kinda observe what he was doing through the window – far enough away, but you know what I'm saying?
R: Right.
P: And give him a little bit more freedom – a little bit more and a little bit more.
R: So some independent functioning and you've seen that happen.
P: Yes.
R: And that was your expectation – functional things for him.
P: Right. I'm looking at it practically – not so much mechanically, but practically. When he went to the store – when we took him down to the mall-store – and he wanted something and I wasn't going to pick the stuff out for him – you know, [I told him] "go pick something out." Then when he picked something out, I said, "What are you doing." Then he explained to me why he wanted a particular item and I said, "Okay – it's cool with me – I don't care." I was just trying to find out where his logic was when he was thinking about buying that particular item. Participant # 3, Page 7

P: I know this sounds funny, but I really don't have any expectations. I said that from the beginning because I've talked to people who expected to have their spouse at 100% and they were very distraught and all – well, that was a very bad experience. Well, the way I see it – I would love to have [my husband] at 100% - realistically is that going to happen right now, probably not – so I am taking each day as it comes – and you know, if he gets to 50 or 60 or 70 and as long as [my husband] can do and we can have a half-way decent life then that's all I'm expecting at this point.
R: So, when you say that he can "do and have a half –way decent life" what is that?
P: So that he can actually function and be able to be with the kids and go and do things that we might want to do. You know, of course [my husband] is not going to be able to do a lot of things that he was able to do prior to the injury, but he and I both know that – so it's learning to cope with those things and gaining skills, I guess, to be able to cope with his disability at this point. Participant # 4, Page 5

P: Well, me and him, wanting to spend time fishing – things he likes to do and things I like to do too. You know, he loves to trout fish and we used to do a lot of that before he went in the service – camping, stuff like that.
R: So you expect that he will be able to do those activities by the time he leaves here.
P: Oh, yes. Yah, he's already practicing casting that rod in bed.
R: That's great.
P: I think he'll be able to do all that stuff. He might need a little supervising along the way. Participant # 6, Page 3

P: A world of knowledge.

R: Ok.
P: Um, a great experience.
Participant # 7, Page 8

P: My expectation is to be knowledgeable on how to take care of him once he leaves this facility – point of contacts, I won't say hotlines, but a person I can call 24/7 and say, look I have a situation, what do I do, who do I need to call. You know, just information once I leave here. Even if I'm not taking care of him, even if I have a situation regarding him or one of the family members because of my son – is there anyone I can talk to or be directed to.
R: So, education for you and some learning the resources – so some things for you personally.
P: Yes. Participant # 8, Page 6

P: I am hoping this is a learning facility for me, as well. Because I need to know how far [my son] is going to come along and be able to know what to do for [my son] when I take him home. That is why I was asking the nurses, is there a library here – I mean, I'm thinking TBI, I'm thinking even neurosurgery only because now the shunt is compromised, I'm not so worried about the port, a port is a port, central lines, etc. But, the shunt, the shunt is huge to me and nothing is being said about contamination of the shunt, but the neurosurgeons said today, what we might need to do is do a spinal tap and get some fluid and check it out and we don't want to top this [pointing to her head] because that's again penetration and exposure to contamination – no, we don't want to go to the head, we'll take it from the spine. I said, oh, I've been there, spinal tap –ok. You know.
R: So, it sounds like you have expectations for your own learning – ok, so you are expecting education and how to best care for [your son]. And his outcomes are unknown and you are comfortable with that.
P: His outcomes are unknown and before I leave here, I need to have a clear picture of what I can continue to do for [my son] are there other avenues for [my son], you know and it's really sad to say this but, every process we go through, you know, we started out at [military treatment facility] – then to [military treatment facility] – and then to here every area I go through is very gray because everybody only wants me to know so much about that facility. For example, at one time I told [nurse at [military treatment facility] name removed] why do I have to send him to a polytrauma center what if I see that in Chicago, the Chicago Institute can help [my son] why can't I send him there? Why do I have to here? And she said, you don't have to go here – well, why aren't you giving me this information? Why don't you tell me what my options are? Why don't you tell me I can go to another resource to further work with [my son]? Why do you want to keep him handicap, I guess? Why aren't you open to giving me information, giving me all my possibilities? Tell me where I can go to help him that will benefit him, that will benefit us all together as a family. Why do all these entities hide everything from the parents from the wives from whomever? And it's all about money and it's all about continuing it in certain areas and it's about government versus outside sources, as far as those institutes are concerned. Then

they throw that scenario at you like, well, his insurance is not going to cover certain things that they do over there. Why not? Why not? Why are you covering him here and not over there? It doesn't make any sense to me. And all [the nurse at [military treatment facility]] said to me was, you're a very smart women, Mrs. [name removed]. You know, even having an insurance background, I dealt with what this insurance policy says here. Now, educated me here [laughing] what else can I do that will benefit [my son], because to me there's never a stand-still. Let's say we left tomorrow and [my son] had only progressed so far, but not enough to do anything for himself, not enough to take care of himself in any way and I still need to know what we can do for [my son] to help him get there because it doesn't stop. How many people wake up two years down the road? You know? You just never know. You just never know what God is going to send you? And in my mind, this is where we're at. This is where where're at. I just like to know what my resources are; I like to know what my avenues are. I like to be educated in what I can do better for [my son].
Participant # 9, Page 20

P: My experience or his experience?
R: What do you expect to get out of your experience?
P: Well, I feel like by my attending his speech therapy, that enables me to turn it all around and make up my own things as we go along, not mention that she has given me a good resource which I am going to order that will allow me to supplement his speech at home too. So, that's definitely my biggest thing is that I will be able to go on and do the speech therapy at home too.
R: So, you're expecting to get education and training and resources on how to help him.
P: Especially in the speech area. Physically, I think he is going to be fine, but I think his speech will be an issue for a long time. It's not coming to me formally, but I think I might be making the speech ladies uncomfortable. I try to explain why I'm doing this – not that I distrust [them] or anything, I just want to be a fly on the wall and just making notes about the way you do things so that I know that I will up to structuring these lessons at home and I want to be able to pull it all together from a teacher perspective and duplicate this. Participant # 10, Page14

P: Satisfaction knowing that [my son] can be everything he's going to be. Everything he deserves to be.
R: Can you be a little more specific?
P: Get his independence back. Um, walking. Talking he does very well on his own now [laughs]. Um, just knowing that he can make it again.
R: So, you mentioned some functional outcomes, like that he could be independent and some walking. And they expect that will happen before he leaves here?
P: He may not be walking like he should, because his prosthetics will be either done in Texas or [military treatment facility] or [military treatment facility]. Um,

> but they're gonna prep him for them. So, and I think once he starts that everything from there will be a breeze and I think he's going to come out of this smelling like a rose. I can just see it.
> Participant # 11, Page 7

Opinions of the current program of care. The following narratives provide evidence that participants are very satisfied with the medical and health information provided to them by the treatment team and that the information is presented in a way that is understandable.

> P: Well, I know he has the traumatic brain injury and Dr. [medical director] showed us the CT scans and showed us the level of damage to his temporal lobe. I know that given that damage, he is doing pretty well considering – and he is and will have some issues related to it and there are going to be some things that he is going to have to work through for the long-term.
> R: And you know what those issues are.
> P: Memory, organization, directional type things – I've kind of noticed that walking around with him in the hospital. He seems to kind of not really know where he's going sometimes. So, I know to kind of be prepared for stuff like that. Dr. [medical director] also told us he could also have some seizures later on in life, so I know that could be an issue to at some point, maybe – hopefully not, but that it could. So, I do know, for the most part, his prognosis – for the most part. And his treatment has been great – I think it's been very well geared toward what he needs.
> R: So you are satisfied now with the level of information that you are getting and that it's presented in a way that you can understand it.
> P: Oh, yah. Participant #1, Page 3

> P: Actually, that goes back to the medical community – I know everything. Absolutely everything. Um, more so now that we've been here – than when we were at [military treatment facility]. At Water Reed there're thousands of doctors and thousands of interns and residents and mix-mashing and everything coming and going – once we got here, we've been just absolutely so impressed because we have been informed – same nurses, same doctors, constant visits, constant care. The first thing I noticed – even if there was a brain injury and the patient is confused, they talk directly to the patient and they fill the family in, as well. They have kept us in the loop – constant information – from day 1.
> R: You felt like you have had enough information and that you could understand the information that was provided to you.
> P: They talk on the same level – in laymen's terms – so we know what is going on. There's no questions and if we have question, they've answered them immediately. Absolutely everything. Participant # 2, Page 2

P: Well, the prognosis is good. With some speech therapy that is being set up though [social worker] up in CT – she is talking with local people back at the home of record where we're take him for his convalescent leave – like 2 or 3 times per week, he is gonna go to speech therapy with whoever they set him up with. And then it will be reviewed in 30 days of whether he needs an additional 30 days on convalescent leave – if not then he'll have to report back to station – and will probably be put on "lim-du" [limited duty] for up to 6 months before he gets a PEB (physical evaluation board). Am I screwing you up with all the military talk?
R: Nope. I was going to comment that it sounds like all of your medical training and your military training has been very helpful through this entire process. You're able to understand a lot of the medical terminology and also how to kinda navigate all the paperwork in the military.
P: Yup.
R: Anything else you'd like to say about that? About his condition and treatment, no unanswered questions or confusion or fog about what is going on with him?
P: Nope. Participant #3, Page 4

P: Well, I know since he's been here, he's made tremendous recovery, you know. And – I don't know if he'll ever be the same person he was, but I think he is gonna be close.
R: Are you satisfied that you have as much information as you want and you feel you know as much as you need to about his medical condition?
P: Yes, ma'am.
R: Alright.
P: Yah, the doctors have been real good about that stuff, what to expect and all.
R: Ok. Participant #6, Page 2

P: I know that he has between 4 and 8 weeks here. Um, his condition, you know because of the head injury, he's lost all left (side) of his eye sight and I know that is something he is just going to have to learn to compensate for and they're teaching him that here. I know that he's go a stability problem and they're of course working with that in all of his therapies. Prognosis – nobody really can give you a prognosis – 'cause everybody's different, don't know how the body is going to heal, but in my own personal opinion, he's at 80% right now. That's my child –joking-cuttin' up – being [my son] in that room with his feet propped up at the end of the bed – that's the child I know. So, as far as, you know, if he were to go home today, he'd be ok. He'd need help all the time, but he'd be ok. He's at 80%. And from what I've seen already it can't do nothing but get better here – he's only been here a week, so it's not going to do anything, but get better.
R: And you feel like you have as much information as you need –there's not – other than the typical unknowns associated with brain injury rehab – you feel like you have all of your answers and if you come up with a questions, you feel

comfortable that you can get the answer and you have as much medical information as you need about his condition.
P: Yes. Dr. [medical director] is wonderful. Yah, just wonderful. Participant # 7, Page 6

P: His treatment, um, what do I know about his treatment. I basically know – I get the update from the social worker at least weekly from the social worker. To my understanding, his progress is still undecided; they don't know how much he is going to progress from this injury. Basically it is day by day, week by week, and month by month. I have not received anything definite – nothings definite saying that 'by this time he will be or he should be at this point.' So, nothing's definite.
R: So, how do you deal with that unknown or that ambiguity?
P: I guess I basically came to accept that it is unknown because of my somewhat research on this TBI. From my understanding, my reading, everyone is different, there's different brain damage, it depends on where it's at – it's just a brain is a brain of it's own, if that makes sense.
R: Yes. Um-hm. Absolutely.
P: So, you know, I can understand what they are saying when I'm told they don't really know how much or how fast he is going to recover from this. Because it's not like a broken leg or arm. I don't know everyone is different and the brain is totally different from a limb or something like that.
R: So, it sound like you got some of that information from the medical staff here, but educating yourself with other resources was helpful in reinforcing what they said. Participant # 8, Page 2

P: And as far as his prognosis, I like Dr. [medical director]'s approach to that – you know, and I do know [my son]'s injury is quite severe and it has crossed both hemispheres and he has a piece of shrapnel in head and you really don't have an answer for me. I think that's what I understand the most. On a, what's it call Glasgow scale and all these other scales that are invented for this purpose, I'm like – I have to look broader than that. I mean I think they're real somebody took the time to experiment, but still its exactly that – still in the experimental stages.
R: So, you seem to be comfortable with the unknown and realize-
P: I have to be-
R: -that there aren't any answers right now. Participant # 9, Page 14

P: [Takes a big deep breath and sigh and laughs] There has been very little said about prognosis. Early on in Landstuhl they talked about prognosis, maybe a little bit in [military treatment facility] ICU. Prognosis according to, what I understood, was we might expect him to recover somewhat, but to never reach full recovery, never be able to live without assistance and not be able to hold down a job of any sort. That's kind of what we were led to believe, so in our

> eyes, he's come leaps and bounds passed from that, within a month he was already passed that.
> R: How comfortable are you that you are getting as much information as you need and that information is being communicated to you in a way you understand.
> P: Yes, several times it's been put to us in such terms as, no one had a crystal ball here we can't tell what the future holds, however, statistics would show that, "da-da-da-da-da." So, I do understand that. I do know it's unknown and that it can take any direction – it may be full recovery, it may not. Participant # 10, Page 10

One mother, who reported satisfaction with understanding her son's condition treatment, condition, and prognosis, talks about disagreeing with the opinions of the medical professionals who were treating their son.

> P: I know the therapy; they want him to be all he can be. Um, the condition, I think is, um, he's got a long way to go. But, he's – they're doing what they can. So, I don't know – I really don't know how to answer that because what I believe and what they tell me is actually going to happen are two different things.
> R: Ok, can you tell me a little more about that?
> P: I believe he's going to see again. You know, it's not going to be great, but I think there is hope as long as he can see shadows. Um, and I think learning all the brail and all the stuff for the blind is great - I'm sure it will help him – but, I really think he's gonna see again and I don't think they [have] the same outlook on that that I do or that [my son] does. And I think it brings him down, but his prognosis, I think, either way is going to be good. Because he's strong- he's accepting it.
> R: Right. He's accepting it.
> P: Mm-hm.
> R: So, you believe that he is going to see again-
> P: I do.
> R: -and what information are you getting from the medical professionals here?
> P: That the shadows that he sees may not be real.
> R: Ok.
> P: And like I tried to tell that eye doctor, I'm sorry, if you're standing beside him and you're not saying a word, and he just reaches out to touch you because he sees something, how can that not be real? You know, for no reason? And he's done it several times. So, it's little things that I see and listening to him talk – and at first I thought maybe it was just a deal – but, the peripheral vision part of it was never damaged. So, you know, I don't know.
> R: So, they're telling you that he is not going to regain his sight, but you're seeing evidence to the contrary.
> P: Right. And I really believe that he's gonna get it – he's gonna get enough back to where he can see and help himself a little. It's not going to be 100%.
> R: Ok.
> P: Now, that's my opinion and that's my belief. Participant #11, Page 2

Stress management among participants. Participants reported managing their stress with a range and combination of techniques that included distraction, catharsis, seeking emotional support from others, self-care, and smoking (40%). One participant reported taking a scheduled anti-anxiety medication. Another participant reported that she had a prescription for an anti-anxiety medication, but was not taking it while she was enrolled in the study. Spirituality and qualities of resilience emerge in several of the interviews.

> P: Um, I don't. I don't know – I like to read and keep up with the news – I'm a big-time news and political type of person. So, I do that when I get back to my hotel room at night – I just surf the internet and read the news, but I've never been good at managing stress anyway – so not really.
> R: So you kind of do things like reading or more kind of distracting or relaxing?
> P: More distracting so I don't worry too much about stuff – so I can kind of zone out and think about something else versus, you know.
> Participant # 1, Page 3

> P: [Laughing] – I get a cold. I don't. I don't manage my stress well. I don't sleep.
> R: Can you tell me a bit more – is there anything that you notice that you do that is helpful?
> P: Well, seeing that I am not supposed to smoke, I smoke more.
> R: Smoking more.
> P: Seeing that my folks are coming and they don't know I smoke, there will be no smoking in the next two days [laughing]. Yah, I probably smoke more, but I really try not to because I don't like to leave him that much. So, sometimes I'll go surf the [inter] net. No, I'll tell you what I do and you guys have all probably seen it - is that I read. I've probably read, let's see – I've been gone for 8 or 9 weeks now, I've probably read a good 9 to 12 books. I read constantly. That's how I manage. It's better than drinking. Participant # 2, Page 3

> P: Well, I don't hold it in.
> R: You don't hold it in.
> P: Nope. Bad for your heart – not good for your blood pressure either.
> R: And how do you let it out?
> P: Oh, I tell ya! If I don't like something, I tell you.
> Participant # 3, Page 6

R: Ok. You mentioned decompressing when you go home and that involves drinking coffee and watching TV, and your "breathing treatments" that's smoking, right?
P: Yah.
R: Do you find that you smoke more –as a way to-
P: [Big sigh] You know, last night I did a check on myself - I was down to a pack and a half a day, which is really good for me, and I have increased up to two and a half and I keep an eye on my packs or try to, so, that will go back down again. Like, my girlfriend, who was on Nicorette gum – and the Nicorette gum wasn't getting her through this – so she jumped back on cigarettes – and now that we're getting to this stage, I talked to her last night, she is now going back to the gum. So, yah, as the stress level went up – that probably went up a little too. That's coming back down again. Participant #3, Page 9

P: I take [prescription anti-depressant], but I've been taking that before [my husband] was injured because I am just an anxious person.
R: How about before his deployment?
P: Yah, I've been taking it for quite sometime – probably 5 or 6 years. I am anxious – I worry. I don't have depression, but I'm anxious and it does not take much to get on my nerves.
R: And you've found that helpful through this process?
P: Pretty much, yah.
R: Anything else you do?
P: A hot shower – just try to get by myself - or vent.
R: So, vent - talking to people.
P: Right – or yelling. I'm very verbal.
R: So you've felt that being able to express some of your concerns has been helpful – has been stress relieving.
P: Yah. Participant # 4, Page 4

P: Well like right now I'm having pain all in here [pointing to left neck and shoulder area].
R: Ok.
P: See, so I hold it all in.
R: So, pain in your shoulder-
P: And I have pains that go through my neck and my eye twitches a lot. Um, I'm just so tense I think is what it is – I'm just holding it all in.
R: So holding it in –
P: Have been. Usually I don't – now when I'm home and I'm upset, usually I'll be upset. But here I've held it in because I want to be there for [my son's wife] and I want to be there for [my son] and I don't want them to think – well, they know it affects me, but they don't know the extent it affects me.

R: So, holding it in, but it sounds like when you get home you'll be able to create some space-
P: Yah, my husband will allow me time. "Cause when all this happened he said, "Why don't you go rest, here let me take the girls." So all that will come up again, but it will be harder because they have not seen their mom for over a month. A month today. So, it's not going to be like, "let mommy rest." Um, but my oldest goes to school and we are going to see if the youngest can go back to the babysitter for a couple days - see that was one way for us to save money was to take our youngest out of daycare. So, we don't even know if she is going to have a spot for her anymore when I get back. But, I'll have the ride home – 8 hours to unwind, but that won't be all I need. Participant # 7, Page 7

P: I don't manage my stress. 'Cause as you know, I need a massage [laughing]. No, I don't manage my stress. Actually, I've been less stressed here than I've been in a long time – I said to the nurse yesterday – I can absolutely tell you I am exhausted today – my cheeks hurt, that's how exhausted I am. I can feel my cheeks in my face [laughing].
R: Your cheeks are hurting from laughing or from tension? You use laughter-
P: I do. I do. I use humor and laughter as a form of getting by things. I think it was a chaplain who said to me, no matter what, you still have a smile on your face. I said, could you imagine how miserable I'd be if I didn't have a smile on my face? And I said, I just can't even imagine that.
R: You are saying things that I feel you should be having a different reaction to. You appear so together.
P: You know, [laughing] you have your moments. You have your moments when you just sit by yourself and you just cry. And you know – and you'll have your moments when you'll yell at God. Those are very private moments. And you ask [to God], what the hell did you do this for? What the hell is this all supposed to mean? Are you punishing me? Is there a message here? Are we supposed to get it? Is [my son] going to get up and walk tomorrow or what? You ask all those questions and they come at intervals you know because you go through so many things when – I think when [my son] came down with meningitis I was thinking – oh, you have got to be kidding me…So, stress, stress is there and stress I deal with through laughter and having a happy moment even it it's just with the nurses about something silly that happens. You know as far as – what I used to do for stress is take a 30 minute walk at lunch because my job is very stressful – I take a 30 minute walk at lunch, you know. After work I would, especially Fridays, we had a Friday night dinner group where we would all pick a different restaurant to go to and it was all women. And you know those things are gone – that's not what I do here. Here I am literally with [my son] from the time I get here until 10 o'clock at night. Participant # 9, Pages 16 and 17

P: [Whispering] I smoke – I'm bad [laughing]. I've been smoking a whole bunch more.

R: So your smoking has increased.
P: I would think it has, yes, because that's how I deal with stress.
R: All right. Good. Well, that's not good, but –
P: I bite on my finger nails too when I don't have my nails done [laughing].
R: Ok, so smoking, biting your nails – anything do you that you would say is a good way you manage your stress?
P: Well, my little sister – I've four sisters, there's five of us girls. My little sister and I talk all the time and so talking to her. When I'm upset, I go back to the hotel room and I vent to her about everything that's happened – what the kids are doing and what's not going right and she puts it all in perspective for me.
R: Ok. So, that helps you feel better and reduces your stress.
P: Yes. And grandma – she's not my grandma. She's actually my ex-mother in law, but my mom died when I was 18 and that was about the time when I was dating her son and we were together for about 18 years and throughout all of this, she's still mom to me and I talk to her about every other day when I'm at home, but here I talk to her about once a week. But, she helps me keep things in perspective too. So, I have those two people who are great support for me. So, they're good for me. So, that's what I do – I rant and rave and then say, taking you for talking to me – I feel better.
R: So, talking it out and processing it and-
P: Yes. That's what I do. Participant # 10, Page 11

P: I smoke cigarettes [laughs].
R: [Reflects laughter – tension break].
P: I read. Like I say, I smoke cigarettes.
R: So you, um, has your smoking increased?
P: No, actually it hasn't. If I feel like something's building up, I'll either go outside and smoke a cigarette – and of course, I'm the world's worst - I'll call my boy friend. You know he pretty much keeps me calm. I wish it were that he could stay all the time.
R: Sure.
P: He was the one that was here – well, you didn't get to see him – for the last two weeks. He let me rant and rave if I'm mad or stressed.
R: Right.
P: And after that I'm fine.
R: Yah.
P: But, usually I'll go have a cigarette or I'll call him on the phone.
R: Ok.
P: So, if you see me rushing out of here [laughing]-
R: [Laughing] get out of your way!
P: [Laughing] yah.
R: So, it sounds like a combination of smoking, something it sounds like you have done for years, and kind of being able to talk to somebody or being able to have that – being able to vent or have that support. And you find that's very relieving.

P: [Shaking head yes] Mm-hm. Or I'll read. I'll just go find a corner somewhere and just read. I'm better off if I'm by myself [laughs].
R: Better off if I'm by myself.
P: Yah.
R: Because...
P: If I get too stressed and you ask me questions then I'm liable to say things that don't need to be said - anger.
R: Sure.
P: And I just – and I've learned that over the years. I just – just let me go have a cigarette and we can deal with it. Well, at least I don't turn to alcohol.
R: Ok. Participant # 11, Page 6

Some family members rely on their faith and resilience to buffer and/or manage their stress.

So, since that time, no one really addressed his prognosis, I guess I could force them to do it and I think that's what his [biological father] tried to do, but to me, I'm one who, I don't need to define it – I'm happy to go along with the flow and let things go where they may and I can take it no matter where it is, but he [the biological father] seemed to need to define it and know exactly what we're looking at in the future and who's going to take care of him and you know, if he's a vegetable and that's where they were all going. Participant #10, Page 10

P: Well, I really don't let things get to me like some people do, you know? I just kinda take it as it comes. Like I say, the more improvement he makes, the easier it is on me.
R: Ok, so focusing on the improvements he makes.
P: Yup. Just don't let it get to me. I've always been able to do that for some reason. Some people tend to dwell on stuff, but try to keep moving forward. Look at the bright side. Participant # 6, Page 2

I don't break, I just bend. Participant # 3, Page 8

R: So, you seem to be comfortable with the unknown and realize-
P: I have to be-
R: -that there aren't any answers right now. Participant # 9, Page 14

P: [Researcher and participant both release a deep breath and say "taking deep breaths" at the same time]. I do go out. I do go out and spend some time taking care of myself, you know, like go get my hair done and nails done – personal needs. You know, like I said, after I saw that there was progress with [my son] I

felt like I could go out and do more things instead of just staying here or staying by the phone waiting for someone to call me – like I need to rush in here. I have two other boys at home and so now we're able to go out and go out to eat and I do go to the movies when I'm here. You know, just a little entertainment and come back and be refreshed. I have learned – even before this incident I have learned – I had to learn how to handle stress. So, I was prepared for any moment that I'm going to be stressed I know that I need to get back and um – regroup or whatever.
R: Sounds like you have had some practice or training in the past – that you are relying on to get you through this.
P: Yes. Exactly.
R: Maybe those situations have made you stronger and able to tolerate this a little more.
P: [Looks a little shocked] I believe so! You know, because I'm just like, I got this.
R: Kind of a shock to yourself.
P: Yes, not only a shock to me, but to my family members because I was in a stressful job and when this situation happened with [my son] they were just waiting for me to breakdown or something like that – but I was ok, I was like, this is nothing. I believe you are right – like I was being prepared for this here.
Participant #8, Page 5.

P: So, it's chaos. But, it's chaos when I'm home too, you know, because when you have four kids life's just – you know, you don't plan too far ahead because life changes on a daily basis and I'm a teacher by nature, so I am used to following things by a lesson plan and having that kind of organization in my life, but as I've had four children, I've understood that you just throw it all out the window and it doesn't really matter what you plan – you just have to be willing to be flexible and go with the flow. Participant #10, Page 2

R: Sure. Absolutely.
P: I'm hanging on to hope for that [points her finger up in the air].
R: You're hanging on to hope. You pointed-
P: To that one up there. And I think He's going to help [my son] get some of it back.
R: Ok. So, you think God is going to-
P: I think he's gonna – I think the shadows are gonna get a little stronger as the eye fully heals.
R: So you have a really strong faith and you are holding on to that and that seems like it's been-
P: But, like I say, I've also seen [my son] reach out and touch- you know?
R: So, it sounds like you have kind of a - kind of a faith and hope that you can't see, but it sounds like you are also picking up on some things that are very real to you that you can see and touch here that are giving you hope, as well.

P: Like I said, if he sets his cup on his table, and you move it, you know, he knows it's not there and he'll look sideways and it's like he's looking for a shadow or something and then he'll reach right toward it. You know, it may not always be right in his grasp, but he'll reach right toward it.
R: Right. Ok.
P: So, I just, I really feel like there might be something there, it just may not be strong enough yet – so, let it heal. Participant #11, Page 2

And I tried many different ways to get us the help we needed to be there, but you know – I'm a Christian and I have this faith that God works things out and he does – so we got over there to Germany – got to seeing things - Landstuhl was excellent – and then when it got time to come home, I ended up having to buy a ticket for $479, but at the same time as me having to pay for that ticket, somebody at home, from our church, a family, who we know well – gave us $500 because they felt led to do so and I told them that $500 essentially paid for my ticket home and a $50 charge for [my husband] to change his plane ticket. Participant #10, Page 6

But, I had faith from the start that we were going to get passed that and we have, so I haven't asked for a prognosis. Maybe if I'd of asked I would have gotten one, but I really haven't asked. Participant #10, Page 10

You have your moments when you just sit by yourself and you just cry. And you know – and you'll have your moments when you'll yell at God. Those are very private moments. And you ask [to God], what the hell did you do this for? What the hell is this all supposed to mean? Are you punishing me? Is there a message here? Are we supposed to get it? Is [my son] going to get up and walk tomorrow or what? You ask all those questions and they come at intervals you know because you go through so many things when – I think when [my son] came down with meningitis I was thinking – oh, you have got to be kidding me. Meningitis? And now he has a shunt in his head and everything is going to ripped out of him: central line, shunt. Anything that's in his body is going to get ripped out and I was so devastated that I went into the surgical ICU desk, right outside [my son]'s room and put my head in my hands. And someone tapped me on the back, and I knew who it was, and I said Chaplin [name removed] how the hell do you know where I am when these things are happening – do you have a camera on me and you guys know where I am all the time and he said, well, you know I do have a connection. He said, what are we doing here? [She then imitates herself in moderate hysterics talking to the Chaplin about her son's condition]. He was a great person because he was he was – he was always there when something went wrong. And did not know how this man knew where I was sitting or standing and sometimes I went to look for him and sometimes he found me, but I fell apart that day. Participant #9, Page 16

R: You're ok with that uncertainty and that unknown and that it's typical with brain injury.
P: And I think it boils down to your, faith, your faith in God, for me faith in God, so I don't, this all, this doesn't, to me it's putting my faith in God and knowing that God will take care of things the way he wants them to be taken care of and I have that faith and if I didn't I'd probably have to be someone who worried more about what the future holds, but I define it in a different way than other people.
R: So, your faith allows you to be more comfortable with unknowns because God is in control of that and why worry about it.
P: Yes, that's exactly how I feel. Participant #10, Page 10

A Hispanic/Latina mother discusses how she feels she feel misunderstood when it comes to other's opinions of how she is managing her stress. Her role as mother, that she emphasizes, defined by her culture buffers her from any role ambiguity as a potential source of stress.

P: Anyway, um, there's just a certain amount of mother responsibility and that's, that was something that I had to relay to the doctors because everyone was saying, you need to have time to yourself, you need to rest, you need to do this, you need to that, and I said, do you guys not get it? I said, um, this is a cultural thing. And I think the Oriental people can relate, as far as being Mexican and my son being injured, this is my place – this is where I am supposed to be. And in my mind, there's nothing else more important right now. In my children's minds, they totally understand why I'm here. Why are you guys having such a hard time understanding why I'm here and why I'm by his side and why I would rather be here than anywhere else.
R: Right.
P: And I said to one of the doctors, I said, you know that concept – and I'm gonna say it – you know that concept that white people have that once your 18, your out of here. That does not happen in Mexican families. They're our babies – if they're 40 – they're still our babies. And we love to see them grow and expand and become their own person – we just love that image of them, but we never let them go – they're never not our children. And they're never not important to us. They never lose our connection to them. In your culture what you do is you know that your child is going to grow and have their own ideas and move away, whether it's their choice to move away at college or established themselves after they finish college and have their own job and want to be their own person, you totally accept that, but the moment – but they should never feel that they can never come back home ever.
R: And you would never feel that you couldn't be a caregiver to him.
P: I never would feel encumbered by their presence. That's just not something you do. You can ask anyone in my family – well, what would you do with your

loved-one – and that's extensions of my family – my sister-in-law and her family [says] well what do they think you're supposed to do – I said, I don't know. [laughing] Go play bingo? I don't know, go do something for myself – which they don't understand – what I was doing at [military treatment facility] was – like from 4-8pm – I took off, I went back to my room, um, I took a nap and get up and fix something there or go to a restaurant or go look around and shop or whatever the heck it was and then come back and be at the hospital by 8-8:30. Because at the end of the day, I wanted [my son] to know that when we say our prayers at night, he was gonna sleep. And that was kind of my way of separating the day for him. I would tell him, ok – it's almost 4 and you and I are gonna take a nap, so I'm gonna go back to my room and I would tell him what my plans were. Or, I saw this really great restaurant and I think I'm gonna go check it out because your uncle [name removed] is visiting. And we're gonna go check it out. And when I went to Florida, I did not leave him alone – I talked to my son and my brother and my son were here with him. And I was able to go to Florida and that just about took the life out of me because those guys do not know to tell the nurse blah-blah. But, I said, ok, they're all guys and they can ride the wave and that was my first real separation from [my son] and that's the only time I've left him.
R: And to you, that's health, and that's functioning and you couldn't imagine it any other way.
P: So, you know, it gets tiresome after a while, I finally told this one doctor, I said, do you realize that everyday I leave this hospital, every time I leave this hospital, my son could be gone. I said, do you think I would be happy if that happened? And she just looked at me and [I] she said, you're the ones telling me how terrible it is and that I should be expecting the worse, so I should be expecting the worst, so why would I separate myself and take that chance? It's where that person comes from, what culture they're dealing with, and you can't possibly know everything about everyone.
R: Sure. Sure.
P: But, my day would be here. My day would be with [my son]. Right now I don't have transportation in the sense of – there I had a rental – the Yellow Ribbon Foundation supplied cars for the families.
R: You could use a car here.
P: I could really use a car here. Especially since it's so detached from everything – um, at [military treatment facility] you could just go up the street and you were in Maryland and there was a little shopping center – I'm not sure where anything it right now.
R: When Mrs. [name removed - Hispanic] was here she took me to the grocery store. And they said, whatever you need, whatever you need. Again, that's the thing between the families and the similarities between the cultures.
Participant #9, Page 12

Problems and problem-solving. Overall, participants report few problems they don't know how to solve or have been unable to solve. They report confidence in being

able to solve any problem alone or with the help of a PRC staff member. Mothers with small children at home report the problems of managing their family at home and caring for their injured son miles away from home. Two participants noted they recognize there may be problems to come in the future that they are presently unaware of and are currently unaffected by. The following responses are from participants who report no problems they are not able to solve.

> P: No, I don't think so.
> R: Ok.
> P: None that I can think of. Participant #1, Page 4

> P: Nope. Every time we have had anything come up it has just been taken care of immediately.
> R: Is that mostly inference to the staff or family?
> P: Pretty much staff. The nurses or go to the doctors – the social workers have been right there to help. They know who to contact. Everything – seriously – nothing – we have not had to face anything too bad.
> R: Nothing that you couldn't work though with the staff.
> P: Right. Participant # 2, Page 3

> P: [Big sigh] No, because I became a royal pain in people's butts if I didn't.
> Participants # 3, Page 5

> P: No, no, I'm real happy now. The better he gets the more better I get.
> Participant # 6, Page 2

The following responses from participants who report having no problems they are unable to solve, but then comment on an issue they are working through.

> P: No, not really other than just dealing with TRICARE insurance and stuff because we had to switch regions – because you're in regions with TRICARE, so and we don't know where we're going to be, either here or [military treatment facility] or in [home state name removed]. But, there are no primary care managers for us in [home state].
> R: Though TRICARE.
> P: Through TRICARE – so that's a problem.

R: That's a problem.
P: Any movement toward getting that solved?
R: I've got to talk to [social worker] and then um, [nurse manager] is working on it too. It's just one of those things – we'll be in limbo for a while - typical TRICARE stuff. Participant # 4, Page 4

R: Are there problems that you are facing that you do not know how to solve or have been unable to solve?
P: [Takes a deep breath and chuckles] How I can run my home from here.
R: Ok.
P: No not really. I mean not in this setting here.
R: The military paper work and administrative stuff?
P: Oh, well, I've got TSGLI (Traumatic Injury Protection Under Service Members' Group Life Insurance) problems, but I think I may have worked through that. I was told I had a nurse case manager at [military treatment facility] and was told what her name was, she never made contact with me that whole time, however, when I came here I was told I a have new case manager and her name is [name removed]. And she has come through – she's contacted me several times and I had four or five avenues working on getting this paperwork that need from [military treatment facility] to send on to the people for the TSGLI and of all the people I had working on it and asked about it, she came though. It's been nearly three weeks now and she's the one who contacted me a week ago, a week within speaking of her and she said it's on the way in the mail to you.
R: And she's from [military treatment facility].
P: Well, she's actually out of [military treatment facility], I think her office is in [military treatment facility], but [military treatment facility] and [military treatment facility] kind of go hand in hand with who helps each place. So, she's been good, but however, the nurse case manager there never made contact with our family at all and I didn't even know what she was to do and I kept saying, what's a nurse case manager do and no one up there could really define that. I didn't know how fit into the picture and she never made contact with any of us.
R: You are pretty confident you are able to work through your problems, or at least find the resources here to help you work through them?
P: Yes.
R: I don't know if there is an answer on how best to manage two household 600 miles apart. Participant # 10, Page 10

Two mothers share future issues. One mother speaks to her own adjustment when she leaves the PRC. Another mother speaks to issues related to caring for her son once he is discharged from the PRC.

P: The only thing I'm really worried about is going home and not being able to be comfortable. I mean, my heart is going to be here, but not to say that I'm not

> going to love home. But, I'm just – I'm going back to work. They've already told me that they're not going to put me out front in front of people. They're going to put me at a desk somewhere *else* for a little while. Um, I haven't –you know I've cried three times since I've been here for probably a total of three minutes each time - since I left for [MILITARY TREATMENT FACILITY]. And I feel like that's going to something that's gonna happen when I'm on my way home and I'm just not – I'm not sure how to handle it once I get home because I'm keeping all of it inside and when I get home I'm gonna have to keep it inside because I'll have my girls. And it's like people-friends of mine and people at work-of course my mom and dad don't –they've never been there for me, but my aunt is there for me emotionally – she said, "You are just such a strong person." And I'm thinking, you know I wouldn't call it strength, it's just call it - when you deal with your kids – it's just that you have to you will do what whatever it takes. Participant # 7, Page 6

> My problems are futuristic because I need to take – I don't own a house of my own and I need to take [my son] home and I'm sitting here thinking – well, I have certain legal matters I have to take care of in regard to [my son]....I should already own a house. This is – I'm kicking myself, I should already own a house- I'm 52 years old and I don't own a house. So, I'm thinking, I should have owned a house so all I would be doing is modifications to this house to bring [my son] home – you know, as opposed to needing a house to bring him home to. My daughter and I live in an apartment and we can't do that anymore. [She can no longer live in an apartment because in order for the VA to pay for the modification of a residence to accommodate a veteran with a disability, the house must be owned by the veteran or legal guardian.]
> Participant #9, Pages 14 and 15

Two mothers discuss legal issues pertaining to the care of their sons.

> One is a power of attorney. [My son] has a power of attorney, but do not know where. And I remember us discussing it before he left, but those are the things that parents, go, "Oh, honey, put it with your paperwork and let me know where everything is"...So, now I have to file for guardianship for my son because he's 22 years old and he's an adult. He would be making decisions of own, if he were coherent. Even though I am his natural mother, I still need a guardianship and it has to be specific and that's in the works right now. Participant #9, Page 14

> R: And even being retired military, you still feel helpless in this situation.
> P: Definitely! I have learned to put my priorities in order and right now, those issues are not a priority because I'm focused on [my son] and he is progressing and that's great, but my other personal issue that I'm dealing with is the guardianship and I have to deal with that. And once I deal with that, then I can work on the medical attending orders and when [my son] is close to getting

discharged, then I have to deal with the line of duty investigation (LOD) and what unit is he assigned to and did they start the medical board?
R: So, right now, you're just seeking guardianship before you can work on those other issues-
P: Right. Because right now I don't even have a right – I really don't have a right because he's married and they're not going to talk to me.
R: Mm-hm.
P: And basically he's married and that chain of command – that's a military word, but you know the protocol or whatever – stuff like that.
R: So, help me understand – because he's married and his wife is not communicating with you, as a mother, you have limited ability to help-
P: Exactly.
R: -and to be a mother in this situation.
P: Exactly.
R: Yah – and so you're working on getting guardianship from his wife.
P: Yah – we'll the court date is next week – and if the judge grants whoever – then I can move on from there. And with whatever rights I have I can you know help or push – even though there's an LOD and the unit - I can try to help him out, if I will have those rights – I don't know I can't really do anything until I know what my rights are regarding him.
R: Ok. Best of luck with that situation – is sounds like a difficult process – it must be something very difficult for a mother to have to endure.
P: I wouldn't wish that on anyone. Participant #8, Page 4

Participants express difficulty with managing and understanding the many resources and helping services that exist and/or have been established for severely injured persons within the military, veteran, and civilian communities.

I know there are programs and people that are available to me to help me with the house because things have to be designed for [my son] and right now I don't know what that is. We're just at the beginning stage of his phase 2, and until I know all that he is capable of, I don't know what he needs. But, that's one thing that the social worker does at [military treatment facility]- she tells you there are these people who will help you – they will build a house for you – there are people who will accommodate you with a vehicle- the government will give you a vehicle- designed to carry [your son] because you would need something to transport him in a wheelchair, etc., etc. And I don't know what these resources are – you hear about it, but there are no specifics. I've just tripped over things-
R: You've just tripped over things. Even now – even in 2007.
P: Nothing is handed to you that says "dot dot dot dot dot." Participant # 9, Page 15

> Right now I'm working on the – now the Red Cross helped us out – they put the – of course I mean I took all my liquid cash and used it. Now, I'm on ITO (invitational travel orders – to be paid by the military), but they pay, you know, they usually pay you after it's all over, but once again that's a pain in the butt thing of knowing how much you can bend the rule and not break it. I got them to pay me in partials – that doesn't equal what I would normally bring, so the Red Cross helped me put oil in the house so I don't have to worry about pipes freezing and that kind of thing. And I think the Navy Marine Corps Relief Society is going to help us with, maybe some of the electric – 'cause that house still had to run up there, even though I wasn't there.
> R: Sure.
> P: For the electric and maybe a little bit of help with the mortgage/rent payment – I'm not really sure yet because I have to send them some stuff, but the stuff I need to send them, of course is in [state where he lives]. But they're supposed to – what's going to happen here is they're picking up the tab over at the hotel – that was a confusing part. I was told that it was going to be "comped" (compensated).
> R: Them picking up the bill is –
> P: Somebody was picking up the bill and I didn't need to worry about it – well, what it actually is – and this needs to be explained better – is that they bill is being "comped," meaning a larger group is going to pay that bill, alright, but you have to pay back the larger group – and I think that is going to be my case because I'm on ITOs and the Navy Marine Corps Relief is going to pay for the hotel, so it's paid – so then when I get my money from the travel (office), then I will pay them back that same amount.
> R: So it sounds like you are able to kinda work through some problems and rely on some other agencies to assist you with navigating the situations that have popped up.
> P: Yah. Just trying to figure out what the line chart is – because this group over here can help you with this, but they can't help you with that. And this group here can't help you with this, but they can help you with that. You have to figure out who can help you with what. And everyone's situation is going to be unique – what their regular incomes are – what kind of cash-flow – I just figured it out today because I took all my money outta my account – to have liquid cash in my pocket when this all got started. I have 380 and some odd dollars in service fees at my bank. Because I wasn't worried about the bank right then.
> Participant # 3, Page 5

Impact of the injury on family members. Most participants report elements of growth as a result of the injury. These elements include gaining an altered perspective of life and becoming closer to family members. The elements of growth are threaded with loss and include loss of a certain and clearly defined future within the military, temporary loss of a parent or the additional loss of the remaining parent who was not deployed.

Several participants comment on how the injury has impacted siblings of the injured.

These responses varied by individual.

> P: Well, besides just being away from home for a while – that's been hard and being away from the kids, but that was kind of my choice because I didn't want them to miss a whole lot of school because they're right in the middle of the school year. And, um, I guess the biggest thing is the unknown – especially what is going to happen to him as far as the Army is concerned – if he is going to be able to stay in or not because – that's what I would like to know first and foremost – to see if we are going to have to adjust our family life – big time – as far as careers and things like that – that's the biggest thing – just the unknown, I think, about that aspect of it.
> R: So, the future in the sense that you don't know whether he will stay in and that would be a huge lifestyle change for you all, as well as an occupational change.
> P: Right. Yah.
> R: And more information about that possibly would be more helpful – what his options are going to be
> P: Exactly
> R: - that's a big concern.
> P: Right.
> R: Any other ways it's affected your family? Relationships – or anything like that?
> R: Um, no, I mean, it's been hard on the kids – when I initially told the kids that their father was injured and hurt, they just took it as, ok, well that means dad gets to come home. They don't understand why I've been away from home for so long. So, that's hard because I've always enjoyed being around the children and, you know, I've never had a problem with that – cause I was a stay-at-home mom and went back to school for a while before I went back to work and stuff. So, I've always enjoyed being around the kids – so it's been really hard to be away from them. But, as far as the family as a whole, my family's been great. You know how mother-in-laws can be – they can get on your nerves [laughing]. She's driving me crazy already about, you know, are you guys coming to see us for Thanksgiving – I'm like wait a minute, when he is ready for discharged from here, I want to go home. You know, so that's kind of making me anxious that already she is – you know.
> R: And she is not the one staying with your kids – that's your mom.
> P: No, that's my grandmother, actually. But, my mom and dad live two hours away, so my mom's been coming down to our house on the weekends to help out with the kids and stuff.
> Participant # 1, Page 4

> P: Well, it's brought the two of us closer.
> R: You and [your son].

P: Yes. Extremely close. We were laughing last night – and the joke is that I told Dr. M something about, "Well, we took a shower last night" and he said, "You got to quit saying that." [Laughing] well, you know [participant was assisting her son with his activities of daily living, including assisting him with bathing]. So, it has brought us together emotionally, as well. And I think it has made me realize how important the people in life really truly are. Um, it has taken us away from our family and that's been hard, both being away from my grandchildren, my kids, my significant other, but those people have been extremely understand – on this side.
R: So, geographically you've been separated, but you feel emotionally actually closer to those people and to your son.
P: Exactly, that's a perfect way to say it. We've been separated for a long time, but I feel like they have been right there tied to my hip the whole entire time cause emotionally they've been – if it hadn't been for them, I couldn't have done this [some tears welling in her eyes]. Participant # 2, Page 4

P: Schedules had to be juggled. My daughter who is under the custody of my ex-wife is mad at me because I am spending all this time with [my son]. I explained to her on the phone and in the email that I did not love her any less, just that he needed me more.
R: So, [your son's] sister is feeling some of the –
P: Yah, she feels shunned. And it has nothing to do with that – it has to do with, this is where I needed to be. Now his mother has the opportunity to come down here and be here and she doesn't live any farther than I do and she doesn't work – why she's not here, no idea. We have to figure out a way to juggle my daughter – either though friends for a day or so or something like that. If her mother would have been able to come down here for two days, I would have been able to go away for two days – and I could have spent two days with my daughter – that would have made her feel better. And maybe it would have made [my son] feel better if his mother were here. Right now he's feeling a lot of reluctance – I feel, I believe – that he's feeling reluctant to his mother right now – even more so than he did before the accident because of her lack of participation. Now, when I was on active duty, now – you have to understand – I had to go do my job – so I wasn't there all the time and they had to take me for what I was and get what you can get while I was there.
R: Sure.
P: And it wasn't because I didn't care to be there – it's just, that's the way it was. Now I'm able to and that's why I'm here. My ex-wife voices a different opinion about that. Up in [my home town] - which is one of the reasons why we got divorced and then I just set her straight again – you know, I'm here because I need to be here – and why aren't you? She came up with 15 different excuses and I was like – whatever.
R: So, the way it might have changed your family is that it brought some of these issues up to the surface?

P: Yah, I mean some of that stuff is always lying there. Everybody has a bit of "Days of Our Lives" going on a bit – or in this case "General Hospital." I mean his sister really cares for him, but she is mad at him at the same time because [my son] is stealing dad. That's the way she sees it.
R: How old is she?
P: Thirteen – plus she is going through divorce proceedings and all that kind of stuff. She doesn't like her mother's boyfriend; neither does [my son]. I haven't spent any time with him so I really don't have a personal opinion on him.
Participant # 3, Page 2

P: Well, it's turned our lives upside down. We went from knowing exactly what was going to be going on for the next 5-6 years to we have no clue at this point. We don't know where we are going to be living at, we don't know if he is going to be able to stay in the Army or not. I mean it's pretty much just turned everything upside down – I mean I had to be away from my kids for two months because again the Army would not allow me to bring my kids – which I think is a bunch of crap. You know, it's turned our lives upside down – I had to quit school – so, I've not been able to further my degree at this point and don't know when I'll be able to do so. So, eventually down the road I can see it having some financial hardships – not knowing where we are going to be at. The unknown, I don't like. That's the whole purpose with the military at least there's stability there. I knew until 2009 we were gonna be in [OCONUS location] and then after that we would have known the year prior where we were gonna be next.
Participant # 4, Page 4

P: Mmm. I think it's made 'em closer and made them realize that things can happen unexpectedly, you know, that can change your life, you know. The family is really, well we've always really been close, but this made them realize that these things can happen in life.
R: So through this experience you have been actually able to feel how close you to your family and having a better understanding that these things can happen to anyone.
P: Anybody, anytime. Participant # 6, Page 2

P: I hope if anything they've learned that life is short and enjoy it while you have it. And everything happens for a reason because too many people out there don't realize that. And we've tried to tell people all along after we lost the baby – that's the only thing we've learned out of all this – you just never know. And life is short. So, don't take it for granted. And hopefully if [my son] learns anything out of this – that's what he learns.
R: Appreciate your present moment-
P: Right! Because you just don't know. You know, like a guy at work, his daughter was over in Iraq and when [my son] went over he took a picture of me

and [my son] and all you could see was my big red nose and half of my red face – I was just balling and I had my head on his shoulder and he's got his arm around me looking at the camera and smiling. And he wrote me a note, they sent me a card- because my birthday was up here - and he sent me a card that said - I know you never expected this to happen and you were never prepared, but he's home – so God Bless him that he's home. You know, I'm just like – oh, yah – it could have been just one phone call; "You know I'm sorry your son's lost his life." And that would have lasted for years. Now it's [my son] has some disabilities and he'll compensate for them because that's just the kind of kid he is. And at least I have him for one more day, two more days, three more days – so I'm thankful. Participant # 7, Page 8

P: Well, my two sons, let's see. I don't know how to answer that question because you know, it has affected them, but it's just hard to – my youngest son does not want to be here [on the polytrauma unit] because he does not want to see [my son who is a patient] – he hasn't said this, but of course you see that he doesn't want to be here, because I'll say, I'm going to Richmond, do you want to come and he'll say no I don't want to come. Ok, even when [my son] was at the other hospital [closer to our home] it was like - no. I'd say, I'm getting ready to go to the hospital and he'd say, "I'll see you when you get back." That is my youngest son who just turned 16. He was 15 when it happened.
R: Sounds like it was very difficult for him when it happened.
P: Definitely. His big brother – his strong brother, who can beat anyone – and this happens to his big brother. Now my middle son, on the other hand, it has affected him, but in a different way where he is coping with it – he asks a lot of questions and his questions I answer. And I think he relays the answers to my youngest son. I think that's how my youngest son gets to know how his progress is. Because I'm up here and they might be in school and when they get out they will call and ask what he did today and I will tell him – he did this, but sometimes I have to – like, I'll say, he was walking with his legs, but I have to go into detail – you know, it's not like he was really walking – he used one foot at a time or he was handling ball – but, I to explain not to give him the wrong picture, but that I had to put the ball in his hand he threw, it wasn't a strong throw, but it was the motion of a throw – you know so they can understand – so when they do decide to come up here they won't have this false picture of [my son]. But other family, my brothers and sisters – we've always been close – we've just stayed close and I can't get any closer that what we are.
R: Sounds like they are very supportive.
P: They are – I have sisters and brothers in New York and New Jersey, so they come when their kids are out of school. They come – when it first happened, they came. And I have a nephew who was there the next day and I have a brother who was there within hours. And they see the progress – they've seen from the beginning and they know he his doing well and he's going to do better – he's gonna come out of this, so we are positive people and we know – I tell them it's gonna take time… Participant # 8, Page 5

P: Well, my daughter went back. It was time for finals and her semester went by the wayside. She felt really bad. She didn't want to tell me, but she called me and she was crying and she said, you know, I just couldn't do it, mom. I just can't think. And I said, um, you know what honey, it's just a semester, just chill, don't worry about it, but I do want you ready for the next semester. And she said ok, I promise. And so she had a bit of time off, so she dedicated that time to working and she worked more hours than she usually works because of two things. One, because I was here with [my son] and she did not want to spend that much time in the house alone and [two] she wanted to make extra money. Luckily she has a boyfriend and she and [name removed] will go out to a movie or go out to dinner, but it's not the same as having your mom home and she and I were the only two who lived in the household. So, I think the biggest hardship is on her because, [my other son] although it was hard for him, having been in Iraq before – like I mentioned the other day, [patient's older brother, name removed] got back and [son who is the patient on the PRC] left. They were back to back going to Iraq. And his job [uninjured son] was far more dangerous and he could not understand how this could have possibly happened to [his brother] and as severe as it was – no this isn't going to happen to him – he's going to be ok. [Participant continues to talk about her older son's experiences when he got back from Iraq, describing post-deployment stress reactions].
R: So, your daughter lost her semester. And your other son, having his own reintegration issues, that everyone has when they get back- and then [name removed]'s situation on top of that –
P: My children and I – this is how I describe it to them from the time they were little – if there was a hardship, we went through it together, if there was a grand things happening, we went through it together and that's what builds your family is all the experiences you have together and that's what makes them grow – it helps them become who they are tomorrow. There's nothing wrong with having hardship. The learning process for them as children is like, well, maybe things weren't so great, but this is what we did and it worked. It's kind of like a – the difference between being street smart and being protected all your life. It's huge. Just huge. Now they definitely learned a lot of things along the way and are able – I think they're able to cope better – I think they learned more by experience – good or bad. Good or bad. But, it's never turned out like just nothing's ever been terrible. You know what I mean? It's always been, you could always handle it – you could always take care of it.
R: You're gonna get through it.
P: You're gonna get through it, yah.
R: Yah.
P: And I think that's what helps them and makes them who they are. That's what helped me – that's what makes me who I am. My mother used to say, if there's only one slice of bread and there's a family, take that that piece of bread and cut it into pieces big enough to share with all of them. Oh, yah, that's were supposed to

do, we're supposed to share. As opposed to go to your room and eat it all by yourself.
R: And it sounds like your family is sharing in the care of [your son].
P: My [non-physically injured] son, oh my god, he is so worried, I mean, I know that he is worried about me, he's worried about [his brother], he's worried about the whole picture, like, "mom, cannot handle this all by herself, now I am married and I have two children, and how do I infiltrate that?" And I tell him that, "you have a wife and you are perfectly fine and you need to continue to live your life." [Referencing daughter, name removed] you need to finish college, we took a little set-back, but you continue to move forward. But, when we're home, [my daughter] come back into the picture. And even though she's in college, it's not going to infringe on her because it will be our household again.
R: Right.
P: And that will be more familiarity for [my son], as well. My other son [name removed] will visit anytime he wants to, he is one of these guys were – it's a 12 hour trip, I'll be there in 8 [laughing]. And so, it will work out for us. And his uncle and his aunt, who are crazy about him, they've already told him, you just wake up and you tell us you need a ticket and we'll get you on an airline. If you need a room, we have a room. But, they're sincere. Participant # 9, Page 18

P: If anything, it's pulling some family members together. As far as me and what I have always felt for [my son], I don't see any change. What [my boyfriend] has felt for [my son] - I don't see any change. You know, I'm sure there are going to be adjustments, but right now I don't see where – when I look at him, I don't see any different. It's still [my son].
R: So, it sounds like relationships have either stayed the same or gotten stronger in your family.
P: Stronger – because the family is close anyway. On my side. Now on his dad's side – I can't answer for him. On my side the family has always been – [my son] has always been very family oriented from my side. Um, I have so much more come visit him. But, I can't see where, you know, other than pulling them closer together – other than that, not much has changed. Like I say, as far as I'm concerned.
R: Ok. How about your routine – with you being across the country – do you have children at home?
P: No. [Name removed] is the baby. Um, [my boyfriend]'s family is taking care of the dog. I have friends taking care of my cat. Um, just working – missing work.
R: So, missing work.
P: But, that's ok.
R: Ok. Participant # 11, Page 7

P: Well, that will be seen when we get home, for sure. More than it will now. For right now, it pulls us all different directions and its hard for me to make my

> 13 year old understand that the world is not revolving around her right now, because it's very natural for a 13 year old to be in that very self-centered stage of life. So, she can't understand why her world is being affected by this and that sometimes there's some times bigger things going on in the world and they have to be tended to before her social life.
> R: Right.
> P: Or her going shopping for new blue jeans or tennis shoes.
> R: That is hard to understand at that age.
> P: So, she is having a difficult time with it. I think my little boys are great with it. My 17 year-old is cool with it and he understands and they've all welcomed [my son] as their own brother. But, [my daughter] is the most self-centered of them all and that's been frustrating to me and I'll say [daughter's name removed], think about it, if you were here and there was nobody here with you, wouldn't you want someone to be here with you? If this was [names all of her other children] I would be there with you and I would not leave you. You guys have accepted [named removed – PRC patient] as your brother and for all practical purposes, he is my son – so, just like you guys, I couldn't leave him here all by himself, so you're all gonna have to make due without me and do the best you can and pull together and try to get along so that I can do what I need to do, but it doesn't – she gets off on her 13 year-old stuff – and I tell her, [name removed], I've seen boys here who don't have legs –you get that, honey? So that's been difficult for me because she thinks her whole world is turned upside down because I'm not there to make sure she gets to her social functions because I'm the car pool and the organizer of all social event and the one who grants permission for that.
> Participant #10, Page 12

This same participant explains how the injury impacts non-traditional families. This narrative speaks to some of the struggles that many divorced, blended, and unblended families face when they must all come together in support of the patient.

> P: Yah, and my husband and I talk every night – so we're good. We do have this issue coming into play [She says this as she points down to a piece of paper where, before the interview started, she diagramed how she became to be known by the patient as his mother. She is married to the patient's biological mother's ex-husband (the patient's ex-stepfather) who raised him. When his biological mother got divorced, the patient stayed with his ex-stepfather and when he remarried the study participant, she assumed the role of the patient's mother, at the patient's request.] I don't know if that's worth mentioning – that's probably a new one.
> R: Well, it's pretty typical – it's typical to have blended and unblended families these days and when something like this happens, it brings the families together that were previously doing their own thing in their own area. And now they have to somewhat co-exist in one hospital room, so to speak, so that's how it affects all those ex's and step's.

P: And so that's exactly where I have been this past week. [The participant goes on to talk about the specifics surrounding the divorce between the patient's biological mother and his biological father and between the patient's biological mother and ex-step father, who is now the participant's husband]. So, she [the patient's mother/the participant's husband's ex-wife] is reaching out to my husband for emotional support and of course that puts me in an awkward position because I am here and I know that she is calling him all the time and they're having very long conversations – things like that, yet I hurt for her mother to mother. And I empathize with her mother to mother, but I also told her, all along, all [she] has to do is pick up a phone and call me. I'm trying very hard to communicate what's going on [here] with her and [my son's biological father]. Sometimes I get busy, know that it is not intentional, but feel free to call my cell phone any time. I have to turn it off when I am in the hospital, but I check it every 3 hours and I'll call you right back with any information that I have. Please know that you are able to call me and I'll give you anything you want to know. Instead, she has never called me, she just calls my husband and asks him what's going on and so I think it is her not her wanting to know what's going on with [patient name removed], but her wanting to talk with – well, I don't want to assume what her motives are. Well, she wrote him an email and signed it "Love, [name removed]" and that was inappropriate. And that's when all this started. She has emailed him on and off over the last seven years and he'll let me read them – we have no secrets - and she's never signed it "Love, [name removed]." So, after these long conversations she's having with him, she's feeling something different – and signed that email that way. So, now she's crossed the line now – so he told her this morning – [interrupts herself and says to the interviewer], you don't want to hear all this stuff [laughing].
R: But it's very much a part of your experience.
P: Oh it is – because it is tearing my world upside down.
R: This is very much a part of what you are going through.
P: So, he called me at 6:30 this morning and told me that [name removed] had called him and that I told her that [I] was more than willing to give her the information that she needs and that [he] really did not want to talk to her any more. He said, and [name removed], you crossed the line when you signed "love" on that email and you are just trying to mess with my marriage and you knew that was the wrong thing to do and blah, blah, blah, blah and they had words.
R: Wonderful that he can be direct and you two have a very open relationship with each other. It sounds like, if I had to sum it up, it seems like the situation with [your son]'s injury has kind of exacerbated some issues from the past.
P: Right. I've never had to deal with her before. So, I'm just now getting to know who she is and what's she's about. I'm always someone to trust until you give me a reason not to trust – so, now she's given me reasons to question.
R: Which is another stressor on top of everything.
P: It is my intent to email her before the end of the day.
R: Well, try to get you out of here soon.
P: You tell me if I'm wrong or not, but I am going to address it woman to woman and say, you know [name removed], you know you have crossed a line here, as

> far as our marriage is concerned and you need to seek your emotional support from someone else – your parents or your partner. However, [name removed], I want to assure you, mother to mother, I understand and I will never do wrong by you as far as [the patient] goes and that remains the same, but I am very uncomfortable with this here [pointing to the family tree we made that shows the relationship between her husband and his ex-wife] and I just want you to know that you crossed a line and surely you realize it and we need to fix that, so please don't do anything that's going to jeopardize your relationship with [patient], because of all the people, I have been her ally, I really have. But of all the people out there, even my husband says, don't trust her – but, I have trusted her all along and I have tried to do right by her, but I hope she doesn't burn that bridge because I'm only human and if keeps messing with my husband – [breaks out in laughter] – you know what I mean? I'm trying to be above that and take the higher road, but it's taking all I've got right now. Thank you for listening, dear [to the interviewer]. I needed to vent that.
> R: Yah, no problem.
> P: See, this is what I do to my sister, so there you go.
> R: It's good – before you confront someone - to be able to practice.
> P: You're wishing you didn't ask that question.
> R: No – that's, you know, we want to get a real-world picture and people have these real stressors in their life that exist and it's more common than not.
> Participant #10, Page 12

Study Feasibility

One aim of this study was to test the feasibility of conducting a family needs assessment with family members of the Polytrauma Rehabilitation Center in Richmond, Virginia. Participants provided feedback to the researchers on the FNQ-M and how they were impacted by the interview. During the interviews, participants also offered information related to their openness for future interventions.

Participant opinions of the FNQ-M. During Session 2 of the study, family members were asked their opinions on the surveys they filled out during Session 1 and were prompted for specific information pertaining to the FNQ-M. Overall, participants expressed favorable opinions of the FNQ-M and noted that the specific questions were good and encompassed their range of needs.

I thought they were good surveys. I thought there are some really relevant questions to answer and issues exactly related to what's happened. But, I thought it might help if you had spaces where you could say, well why you feel like your needs may have been unmet or why do you feel like your needs have been met in this situation. Participant #1, Page 1

P: Well, you know, they were helpful.
R: How were they helpful?
P: Well, things, you know…how things been going on…you know things in general…experiences with him.
R: So you felt like they addressed appropriate areas?
P: Mm-hm.
R: You didn't comment that there was anything missing from them…you felt they covered pretty much what your experience has been like and your needs.
P: Sure did.
R: All right. Participant # 4, Page 1

They were good. You know, they asked enough questions. Participant # 7, Page 1

P: They were fair questions. They weren't too difficult or not appropriate.
R: Did you feel they addressed all the areas?
P: If I can recall correctly – the medical or administrative part of the hospital – the right questions were asked.
R: They covered all your needs?
P: Right. I believe so. Participant # 8, Page 1

P: Um, I think they were good surveys. Like I said, you just need to add something about the transportation – find a way to put that in there.
R: So you felt like they encompassed everything you have been dealing with?
P: Um-hm. Participant # 11, Page 1

Two participants, one retired military and one active duty dependent, noted the questions were geared toward a non-military population.

P: I thought they were geared mostly toward the civilian population more than military and since it looks like over 50% of the people up here are military – active duty people- that they need to be tweaked a little bit put more toward the…
R: Focus on active duty issues?
P: Well you have to have the other thing because you not only have the active duty guys up here, but you have the other folks too – or maybe you can have two completely different forms that ask the basic same questions, but one based more

> toward the civilian population and one based more toward to the military population. Participant #3, Page 1

> Some of them did not apply to us, being military. Participant # 4, Page 1

Two participants noted that the questions made them think about their needs and offered them a different perspective.

> P: I thought they were good because it actually made me think about what I thought of everywhere I've been and the processes – I call them phases – the phases I've been through with [my son]. And it's funny because I went back and labeled this phase two because I felt like I was going over so many different scenarios with [my son] between [military treatment facility] and [military treatment facility] and I was. If I reflect – that's a preliminary stage and this is stage two. Like, it was kind of an awareness of how I felt about this and that – and that's good. Participant # 9, Page 1

> P: It made me think harder about things. It brought things to my attention that I don't think I had realized were needs. So, it made me see things from a different perspective. It brought things to my attention that probably should be met, but yet I'm a minimalist on asking for the minimal amount, but if someone might need more or want more.
> R: So, it almost kind of educated you, would you say-
> P: I would. I would.
> R: -on some other areas that need to be addressed that you did not know about?
> P: Exactly. It was an education. Participant #10, Page 1

Impact of the study on participants. Participants offered comments that indicated having an opportunity to express and process their experiences served as an intervention, allowing them scheduled time away from the patient, a distraction away from their routine, time to express and process their experiences, and the opportunity to offer helpful information to others.

> R: What has it been like for you to talk about these issues?
> P: It's been good because it kind of lets you vent a little bit and get some of your feelings and opinions out about the whole thing because – it's kind of hard for me to sit back and not really say what I think – so it's been really good in that aspect

in that I've gotten to tell you what I think about the whole process and kind of get some of the – what you want to say out.
R: And why do you feel like you have not been able to do that all along?
P: Um, maybe because there is not really the environment for it. You know, because I feel like I've been going on – going to his therapies and all that kind of stuff – and it should be geared more toward him and his rehabilitation, but at the same time, you know, you don't really get a chance to talk about how you feel about everything since the moment you got told that your spouse or your son has been injured.
R: So the opportunity maybe to talk specifically about how your feeling, you know – since injury notification-
P: Right.
R: -and kind of process some of that stuff
P: Right.
R: -would be helpful, just for you.
P: Right, just for me. And I don't, it might not be the case for everybody else, but I kind of feel like I have just been going along and not, you know, going through everything else, but I haven't really had the chance to say, well, this is how it made me feel. [My husband] and I have talked a little bit, but you know, still – sometimes I think it would help to have a 3rd person or someone else maybe that you could talk to and say well, hey this is how I felt about what happened and just to kind of get if off your chest without the judgment, so to speak – you know what I mean?
R: Judgment.
P: Well, you know, that your feelings are wrong - for feeling this way – just to be able to say it and get it off your chest
R: To someone who is not your husband or involved in [his treatment].
P: Exactly. Participant # 1, Page 6

P: I would say it's been relaxing. You know, there's no other things going on. You know, I can't think about him because I'm doing this – it's like it's just been relaxing.
R: Relaxing because it's been distracting.
P: Umm-hmm - from the rest of our lives. I referred it to somebody one day that this is my job and this is probably the hardest job I have ever had to do – these last 2 months. Delivering kids and raising them was nothing like helping to bring him back from where he was – and so, it's like a distraction from your job.
Participant # 2, Page 5

P: I think it's good. So that somebody else can find out and something – it's not going to help me at this point, but hopefully by you guys doing this stuff, it's going to help somebody else in the future. There's got to be some better procedures put in effect because this war is not going away. Not any time soon.

And I guarantee that if you go to [military treatment facility], you'll get more than what you are bargaining for. Participant # 4, Page 6

P: I've enjoyed it. It's not been bothersome.
R: A positive experience.
P: Sure has.
Participant # 6, Page 3

Fine. If it helps another family - priceless. That's all I want. I don't expect anything to come out of the grant application. I don't expect anything to be different here, because it's been wonderful here. I don't even have expectation for the [MILITARY TREATMENT FACILITY]. But, I am writing that letter because I feel it is important for me so the next family may not have to go through as much. It would be great if they didn't have to go through anything I went through, but even if just a little bit has changed every time a parent writes or somebody voices an opinion – pretty soon those little things will add up to fixing the system. Fixing the heartbreak and people won't have to go through that. And so that's – as long as I can voice my opinion and maybe make a difference, good. Good. Participant # 7, Page 11

It's just been a relief to talk to someone because you - I really haven't – I talked to a few family members because they are here and some experience, um, but to actually talk to someone, it's a relief. I talked to two parents one night. I was on my way home and I stopped in the computer room and we all stayed, like two hours just talking to the two family members in different situations, you know, and stuff like that, but just to talk and we talked about the experience prior to coming here – and we've all been to different hospitals, so it's basically like the same thing from one hospital to another – you know with the brain patients.
Participant # 8, Page 7

P: It's very, um, relieving. I just um, it makes me feel better. It makes me feel like I can voice my opinion. I don't know how far it will go. I don't care. Like I told you – every time a scenario came up, I said it to whoever would listen because I wanted them to aware. I said it in Spanish so that those people would be aware. Participant # 9, Page 22

P: Oh, well, I'm a talker, so I like it. Like I said, it's like venting to my sister – so, you have been my sister call today. So, that's a good thing. I'll tell my little sister that she got off the hook today – so, thank you for listening.
R: No problem. I realize that [talking with me] is something to add to your list of things that you had to do to do today, but-
P: No, it's actually kind of a stress reliever.

> R: Oh, good.
> P: It's been very pleasant. I enjoyed laughing with you – seeing the light side of all these things.
> Participant # 10, Page 16

> P: Felt kind of good. I have not gotten to do this in a while. It felt kind of nice. Now I'm ready to go fix steak and a birthday cake. Participant 11, Page 9

One retired military father expressed a neutral opinion about the opportunity to talk about his experiences and needs.

> It doesn't hurt me. I've been talking about them. *Participant # 3, Page 9*

Openness for Intervention. Family members made comments about their openness for different interventions pertaining to individual and group support. In a discussion about how she manages her stress, one active duty spouse noted that she would be open to receiving information on stress management.

> R: Ok, and do you feel like that's adequate or do you feel like you might want to learn other methods to manage your stress or do you feel like you're ok with-
> P: Yah, I would like to learn other methods to manage my stress – 'cause like I said, I've never been very good at it anyway. So, I'll admit that about myself [laughing]. Participant # 1, Page 3

Service members who are medically evacuated and (their families) do not go through the standard (and mandatory) reintegration training as non-medically evacuated returning service members. Part of the reintegration training is focused on how family members can help ease and support a service member's immediate exit from a combat zone to a non-combat environment. One mother commented on her openness to receiving more information on how to support her son, specifically how to talk to him about his experiences in Iraq.

P: We eat meals together and he talks with me whenever he's not in therapy. He talks. And even though he's a big boy and he could probably be without me here, on the other hand, I think he needs me here because he will share with me things he won't share with anybody else. He's been remembering everything that's happened and things that happened in the war over there and he needs to share those things with somebody. And I think it's a good thing for him to share and I don't think he would share with [rehabilitation psychologist's name removed] the same way he would share these things with me.
R: How do you feel – do you feel you have enough information and education in helping him process some of those things or deal with some of those things, do you feel like you-
P: I do feel comfortable with it. I think I'm easy to talk to. I don't offer advice unless they want it – that's just what I've found my roll to be. At any rate, so I think I'm good for that, however, it can be overwhelming because there are just some days, you know, it's a stressor to uh,– number one, I have to give him my undivided attention in order to understand him.
R: Because of the brain injury or because of the military lexicon and jargon?
P: All of it - all of it. Just to understand what he's saying, now that that's getting better it's still the military thing because he can't communicate it - so I've got to – now we've got our own little sign language going and he's got a coin he pulls out [she imitates him pointing to crossed rifles, a symbol for the infantry] and that means infantry because he can't say infantry. He did say it the other day, but because of his disorder, it's inconsistent, so one time he may be able to say it and another time he may not.
R: So, not only is he translating military talk for you to understand some of his experiences, he's having some word finding difficulties related to his brain injury that's complicating his ability to communicate with you.
P: Very much so. So, and his numbers are totally off the chart. He'll say we're gonna do this in *three* days and he'll turn around and repeat it and say, we're gonna do this in *seven* days. It doesn't register. Numbers and the number concept are difficult.
R: Right.
R: Do you think it would be helpful if you had specific training on – acute stress reactions or transitional issues for people who are returning from war zone or do you feel that's not-
P: Oh, I think would be – yah. I've been given tid-bits here and there, but never anything formally.
R: How to talk to someone whose coming back war zone.
P: And, you know, he's going through a lot himself. When we go out in public, people are staring at him too, because he's wearing this helmet –it's an adjustment for him. Some people deal with things like that better – he's kind of a temperamental kid.
R: So that's specifically related to his injury and his adjustment to his injury and on top of that there's the returning from a combat zone.

> P: Yah and the doctor told me that it might be rough for him to go out into traffic and we were walking and a rock popped and that scared him – so noises do scare him and we've been told about it a little bit.
> R: So you feel you could benefit from more education on deployment related stress-
> P: And anxiety too. [She begins to tap her hands and her legs in such a way to imitate her son's movements]. So, I don't know anything about this – he's like this [tapping] all the time and that isn't his normal nature, he's like this [she make some anxious type motions with her shoulders and head] – he can't sit still, he has a two-minute attention span and that's not him, really. So, this is injury related, but no one's ever addressed that. Participant # 10, Page 4

One participant commented on her openness to receiving personalized information specific to her son's brain injury and offered recommendations to the staff on how to present this information.

> P: I just think that whatever information is out there for the TBI patient, the family member should – I mean, they have the flyers and the books, you know, in the computer room, but if you're not computer literate – or don't want to be bothered with a computer, you're not going to go in the computer room and look around. If you not a reader like I am – you're going to walk right past it. I'm a reader so I stop and read and pick things up. And I think all that information should be in the patient room – a welcome package – they do give you the orientation book, but it all should be given at once. The case – the situation that my son was in – when you first come in here, you're not going to be looking around for stuff – you're in here – you probably had a bad experience at the last hospital – so you think – you're wondering about this place – are they going to be just like the last hospital and stuff like that. And I'm thinking that when you're in the room, put it in a bag so that you can just pick it up and take it to the hotel or wherever you are going. I'm not saying that night, you're gonna go though that bag – it might be a week or a months, but eventually you'll look through the package and read some information. I wrote on the survey, whatever brain injury the person has there should be a little handout or information on that. My son has frontal lobe damage – give me information on frontal lobe damage. You can give me information on the other areas and polytrauma and different wires of the brain, but give me some information on his damage.
> R: More specific to his injury.
> P: Right and with that and all the other handouts. Participant # 8, Page 7

Two participants commented on their openness to group interventions and being networked to other families.

P: I think it would also help for some of us families to maybe talk to people who have been through this type of situation or are maybe going through it. Um, because I'm not in the military – I understand how the military works, I'm not in it so it would help to talk to other families – if there was, 'cause I think, you know, I've talked to other families that are up here, but it's been kind of hit or miss – it's not where you can sit down and really get to know each other sometimes.
R: So, you feel like if you had the opportunity where all of you could come together and meet, that would be helpful?
P: I think so. An informal type of thing, though, not so much of a formal, just maybe a social type of thing, so you can get to know each other and kind of talk to each other and say, well, what happened, you know, and you get - 'cause I find that helps sometimes even if you just have someone to talk to about it who understands. Participant #1, Page 5

R: So, what do you think about the idea of having a group for family members if there was the underlying assumption that everyone is different and everyone will go through things differently and everyone will progress differently, but there might be some common bonds. Do you think there are enough common bonds to bring everyone together as a group?
P: Yah, definitely. Yes, just by talking to those two.
R: And that would be helpful.
P: And just to come in to talk because a lot of times – it depends on your loved one's situation, but a lot of time you don't leave that room. You leave to eat and you go back in there. And that's how I was at the beginning. And there's a mother here now – her son is not at the state where you can leave him or bring him out. You know, I think having something is a good thing.
Participant # 8, Page 7

Noting the 'trauma' component of a polytrauma, the political climate, the complex nature and sequelae of brain injuries and the variation in recovery between individuals, the psychologists on the polytrauma unit express concerns about bringing such a diverse group together for a therapeutic support group. The following comments shed light on why the psychologists on the polytrauma unit are concerned about bringing such a group together.

P: To any other parent. It's hard. It's hard to hear someone stand up and say things are gonna be fine, and you're standing there thinking, you can't tell me that in all honestly and mean it.
R: Because you know things are uncertain and they will be uncertain for a while.

P: I mean, you know I've listened to other parents say that their children got shot in the arm and had to have a lot of surgeries and I'm thinking, my child's lost his legs and his arms and you want me to believe that he is going to be ok? I never say it out-loud and I am never rude to 'em. Uh, but inside I'm thinking, you know, how can you stand there and tell me that? You're child did not go through what mine did. Each child is different. They feel different. They think different.
R: Right.
P: You know, it finally got to a point where I would eventually say, 'Don't tell me that he's going to be fine – I don't want to hear it.' I'll believe it when I see it. And then and since each day, I see it. But, you know, it's just – it's hard.
Participant # 11, Page 5

R: It makes it kind of hard to find someone to talk to who understands-
P: And that's what I tried to do when I first got here – my thing is, I was here for [my son], but I was also out there trying to get information from other patients or other family members and I was told not to, um, not really do that, but not compare. And I understand that, but at first I didn't understand that because I was out there trying to compare. But, now that I've been here for a while, I see that you can't really compare one patient to another. At first I was trying to compare. Ok, this person's been like this and he been like this since this time and so [my son] has a couple more months – so let's see. I actually was trying to compare, but then I realized – it didn't take me long, but eventually I did realize I couldn't compare one to another. But, then I did talk to parents and it helped me to find out what happened when their loved-one became aware, but it's still different, so you know. But, it gave me – what really helped me was the fact that these patients, once they came here and they came in a similar situation as [my son], not the same thing, but the short-term they became aware and that's what I held on to. Like, ok, this person within 5 weeks he was aware, but this person took a little bit longer, [my son] became aware – they got him out of that one stage he was in - so that's, if they can get him out of that one stage then I can go on from here [talking about her son's emergence from his coma]. Participant #8, Page 2

Chapter V

Discussion and Summary

The purpose of this study was to test the feasibility of a method of assessment to identify the needs of individual family members of service personnel receiving inpatient rehabilitation services at the Polytrauma Rehabilitation Center (PRC) located within the Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia. The study further explored the lived experiences of family members prior to arriving at the PRC and during their time on the PRC. This information was collected with the intent of gaining a better understanding of the needs of families of individuals with severe injury from within a military cultural context and to provide recommendations for the future development of programming to meet the needs of these families. Both quantitative and qualitative data were collected during this study. This chapter will provide a detailed discussion of the results of this study addressing its strengths and limitations. Directions for future research and a proposal for a program of care for families will be provided.

Researcher as Instrument

Results of a qualitative inquiry using of Interpretative Phenomenological Analysis (IPA) are influenced by the researcher (Smith & Osborn, 2004). It is through the exchange between the researcher and the participant that the participants' perception of their experiences are gathered and it is through the lens of the researcher that the information is analyzed, interpreted and reported. Therefore, I would like to present my unique lens, what led me to conduct this study, what my experiences were like conducting this study, and how I have evolved over the course of conducting this study. Interpretation of the data requires the investigator to follow an interpretation procedure,

but also have several personal prerequisites (Ponterotto, 2005). As the PI of the present study, I met these personal prerequisites. The first prerequisite is that the investigator must have direct contact with the study participants and the phenomena under study in its natural setting (meaning the setting is not controlled or manipulated experimentally; Ponterotto, 2005). The Department of Veterans Affairs awarded me a pre-doctoral health rehabilitation research fellowship to conduct this study. I was present on the polytrauma rehabilitation unit at McGuire VAMC for approximately 30 hours per week for nine months. During that time I participated in multidisciplinary treatment team meetings on the unit and interacted with staff, patients and their family members.

Second, the investigator must have personal experiences and insights related to the study participants and the phenomenon; these are an important part of the inquiry and critical to understanding the phenomenon (Ponterotto, 2005). As an Iraq war veteran with 10 years of active military service as an Army officer, I experienced life as a military service member and military family member, and interacted with injured service members as they were awaiting medical evacuation to Germany from Iraq. I also have experience working and interacting with military families who have not experienced a polytrauma. I successfully completed a year-long clinical practicum on an inpatient rehabilitation unit, frequently counseling patients and family members facing a life-changing physical injury. Additionally, I unfortunately experienced the month-long illness and subsequent death of my grandmother while conducting this study. I was with her during her admission to the emergency department and transfer to the intensive care unit; I experienced shock, frustration, confusion, and fear associated with her medical situation. I was able to observe my own family members' reactions to a training hospital, nursing shortages,

multiple doctors, residents, and interns providing different information to different family members at different times. I also identified examples of resilience and strength in myself and my family.

Third, the investigator must have physical, as well as emotional access to the participants. The establishment of rapport, trust, and an expression of genuine empathic concern for the participant, the wounded service member, and the phenomenon being studied are essential when using interpretative phenomenological analysis (Ponterotto, 2005). I feel the counseling psychology doctoral education and practicum training I have received combined with my military experiences has enabled me to me gain emotional access to the participants, meeting them where they are in the redeployment and rehabilitation process.

Several distinct events occurred that led me to conduct this study. This process started when a need was identified by a psychologist at the VA medical center in our local community to provide support for families of patients on the PRC. Working on this project served a need in our community, but also served my own personal need to continue to serve service members while continuing my education. This study began as an inquiry into intervention programs for families of individuals with a TBI. The more I read and reflected on my own personal experiences, the less confident I felt that an established structured intervention program for families in non-military communities would cleanly fit families on the PRC. Including a qualitative component to this study was driven by personal experiences. When I returned from Iraq, I filled out a survey for the Army on my experiences and my reactions to those experiences as I was leaving Iraq. At the time I remember thinking the survey was missing so much. I felt slighted that my

experiences were reduced into little black dots on a Scantron sheet. There were so many things I experienced that the survey did not address. For example, I recorded that I did not see anyone get shot, but nobody asked me about all red dots I saw everyday on our convoy map that represented all the attacks that took place on our supply convoys. As we planned supply missions (under frequent indirect mortar attacks), we tried to do what we could to keep as many vehicles and soldiers off the road as possible, but inevitably we would learn of injuries or deaths that resulted from enemy attacks on these convoys. There was no bubble to darken for this. I think this contributed to me minimizing my experiences and increased feelings that I did not deserve to be sad or angry or anything, but thankful I was alive. I was feeling very different from how I knew I was presenting on the survey. Back in graduate school, I found myself in a counseling psychology contemporary issues class that focused on leadership and multiculturalism, in addition to contemporary issues in counseling psychology. It is here where I fully began to identify with my veteran status and unique cultural experiences, and it is here where I learned about qualitative research. I remember finally feeling relief that there was something else besides Likert scales to scientifically capture and communicate information.

My experiences while conducting this study can best be explained using a sport-related analogy. As a kayaker, climber, and mountain biker I see things in lines. Before you commit to a serious rapid, route, or trail, you must carefully pick your line and weigh the risks and benefits of the different options. Then given that information you fully and freely commit to the challenge. You go where the rapid flows, you climb where crags lead you, and you ride where the trail takes you. There are planning elements and risk assessments you control that are based on what you can see from where you are at the

time, but there are many unknowns that lurk in areas you cannot clearly see. Part of the exhilaration of and growth from the experience comes from the opportunity to see how you will react to unknowns and what you will do with them when encountered. Choosing this study for my dissertation was a risk that I was willing to take given the sense of immediacy surrounding its applicability and unique focus. Although I had an idea at the start of this project of what numbers I wanted and the type of information I was seeking, it is the environment and participants who led the study and I had to follow their lead. The environment on and surrounding the PRC will be explained later in the discussion.

My experiences conducting this study included many challenges. I felt challenged as a scientist, practitioner, and leader. First, I struggled with the research paradigm shift. My previous research and community intervention work focused on early health promotion interventions based on risk factors that were identified though large samples in controlled and manipulated environments. In the present study my job was simply to observe and do as little intervening and manipulating as possible. Second, as a practitioner, I leaned heavily on my clinical skills to quickly establish rapport and trust with participants. I recognize that my clinical interviewing skills and my counseling skills are not mutually exclusive and that both were used at times during the interviews. I found it challenging at times to balance my needs as researcher with my clinical judgment. Finally, leader and leadership variables continued to surface for me during this study. The last time I worked with active duty military personnel, I was in a leadership position that carried serious responsibilities. This study for me was about following and not leading, but I maintained a sense of leader responsibility during this study and looked for it in others.

I have evolved emotionally over the course of this study. This personal growth has inevitably influenced the collection, analysis, and interpretation of the data presented in this study. Guided by the writings of Boss (2006), this study has helped me recognize and better manage the personal, ambiguous and global losses I feel as a result of the current conflict in Iraq. It also has provided me an opportunity to emotionally experience my own emotions and distinguish them from the empathy that I felt for the participant. I took time every week to process my experiences and emotions with a licensed clinical social working in the community who was not affiliated with the VA or VCU.

I leave this experience feeling as if I have only scratched the surface of what life is and will be like for those who care for injured service members. My hope is that this dissertation will make an impact on family care, program development, and program efficacy research. It has been an honor to conduct this research and serve those who care for those who have served all of us.

Environmental Context of the Study

Not every family member present on the PRC was enrolled in this study, although every effort was made to do so. Several potential participants were introduced to the study, but declined. One participant declined because she said that she had already expressed her negative feedback to the Department of Defense and that she had no problems with what she was experiencing at the PRC. Several potential participants were simply too busy caring for their loved-ones and handling all of their personal matters to participate (interviews could only take place Monday – Friday between the hours of 0800 and 1630). One potential participant declined to participate because of legal issues surrounding her family member's injury. One intangible variable that influenced the

sample population was the current political climate. There is a gentle respect for the political environment surrounding returning Operation Iraqi Freedom and Operation Enduring Freedom (OIF/OEF) military personnel and veterans. Although somewhat intangible on the unit, evidence supports the reality of this variable, such as when a staff member was required to remove 12 slides from an APA presentation as per the Department of Defense. Other evidence exists in the form of frequent visits from high-ranking officials and the presence of the top three local VA officials on the PRC when a patient was to being medically evacuated back to WRAMC. The treatment of OIF/OEF personnel is currently a political hot topic that is directly related to the debate over the war in Iraq. There is a defensive posture surrounding many people who work with this population. This defensive posture is built to protect them from attacks that appear to be politically charged. Assumingly, well intentioned efforts of criticism and calls for change to services provided to this population can cause competent and very caring professional to feel discounted and hesitant in working with OIF/OEF personnel. I have come to call this "political PTSD" and recognize it as a product of the environment. It saddens me as a veteran to see it happening. Efforts are continually made to preemptively avoid opening the unit up to any more attention that it already receives to no fault of its own. The present study was not excluded from this. The environment and understandable reactions to the environment by study personnel (not participants) turned the study population into a convenience sample. However, given the present study population, there is still valuable information that can be derived from this study. More information pertaining to the study population will be provided under limitations.

Family Needs Questionnaire – Military (FNQ-M)

One of the main focuses of this study was to test the feasibility and explore the applicability of a structured and efficient family needs assessment. Overall, the FNQ-M appears to be an efficient and effective way to assess family needs. During the present study the only differences between the FNQ and the FNQ-M were the addition of a military support question ("I need to have a military representative to turn to for help with military-related issues") and 10 blank lines where family members could list additional needs not mentioned in the survey.

Date generated by the FNQ-M. Family members rated the importance of their needs in the following order from most important to least important. *Health Information Professional Support* and *Military Support* needs were rated equally as most important (mean = 3.9 out of 4), followed by Community Support Network (mean = 3.7), Involvement with Care (mean = 3.5), Instrumental Support (mean = 3.0), and Emotional Support (mean = 2.8). See Table 4. All domains with the exception of *Emotional Support* and *Instrumental Support* needs were rated as important or very important by the group ($n = 11$). *Involvement with Care* needs were most often rated as met (95.5%) followed by *Health Information* (88.3%), *Community Support Network* (67.6%), *Military Support* (63.6%), *Professional Support* (58.2%), *Instrumental Support* (40.9%), and *Emotional Support* (40.9%). See Table 4. Previously published research indicates that the need for clear and honest health information is typically rated as most important, with personal needs (emotional and instrument support) rated as least important (Mead et al., 2004). The rating of *Emotional Support* and *Instrumental Support* needs as the least important and least often met in this sample is consistent with a previously published study that examined family needs during an inpatient rehabilitation setting. Mead and

colleagues (2004) also reported *Emotional Support* and *Instrumental Support* scales had mean percentages lower than 50%.

It is important to note the level of importance of the need for a community support network in a population that is removed from their military and/or home communities to join the injured person in a treatment facility that is typically at a distance from their communities. One study participant lived just under a two-hour drive from the PRC, but the other participants were not able to return home daily. It is also important to note that many of the military support needs can be classified as instrumental support needs, specifically, family members report needing help with filling out military paperwork (military insurance forms, travel orders, transportation, etc.) and needing personal transportation. The percentage of needs rated as met is valuable information to gauge how well family member needs are being addressed. Quantitative feedback on the program of care offered on the PRC is consistent with what family members presented in the qualitative portion of the study. Family members clearly and consistently provided narrative data that matched the quantitative percentages of needs met as measured by the FNQ-M, indicating that participants are very satisfied with the health information provided to them and that they were very involved in the care of the patients.

FNQ-M item analysis. Due to a small sample size, an informal visual item analysis was conducted. A number of participant responded to two questions as being not applicable. Question #14, "I need to have complete information on drug or alcohol problems and treatment," was rated by five participants (45.5%) as not applicable to them. One of the participants who endorsed this item as not applicable had a family member injured in a motor vehicle accident in the United States. All others who

endorsed this item as not applicable had a family member who was injured in Iraq. Question # 36, "I need to be reassured that it is usual to have strong negative feelings about the patient," was rated by six participants (54.5%) as not applicable to them. Every participant who endorsed this item as not applicable had a family member who sustained an injury in Iraq. One previously published study makes specific comments related to these two items (Livingston & Brooks, 1988). First, these authors note that alcohol is commonly involved in head injury accidents, but that this pattern does not necessarily hold for military head injuries; the injury is a result of a combat situation rather than a "self-induced hazard such as drinking alcohol" (Livingston & Brooks, 1988, p. 6). The authors further suggest that because of this, severely injured soldiers with missile wounds will have different outcomes compared to non-military populations because "family attitudes to the victim will bear some relationship to the nature of the situation in which the injury was sustained, and the extent to which the relative perceives the victim is to blame" (Livingston & Brooks, 1988, p. 7). This study offers a suggestion as to why these two questions were rated by many of the present study participants as not applicable. Most of the injuries of the family members of the participants in the present study were sustained during combat operations due to no fault of the service member.

Participant opinions of the FNQ-M. During Session 2 of the present study, family members were asked their opinions of the surveys they filled out during Session 1 and were prompted for specific information pertaining to the FNQ-M. Overall, participants expressed favorable opinions of the FNQ-M and noted that the specific questions were good and encompassed their range of needs. Additional items that were

added to the blank lines included needs related to transportation and how to navigate resources available to family members.

These results suggest that the existing domains of the FNQ (Kreutzer, 1988) aptly captured the needs of the study population. However, results also suggest that the needs of the present study population extend beyond the existing domains measured by the current FNQ. The added domain of *Military Support* needs was rated equal to *Health Information* and *Professional Support* needs as most important. This information is underscored by the qualitative feedback provided on the FNQ-M. The qualitative data from the present study also suggests that additional questions need to be added to the FNQ-M to capture all the needs family members on the PRC may have. It is recommended that the following questions be added to the FNQ-M for use with a polytrauma family population:

I need...

1. *...to have a military representative from my injured family member's branch of service to turn to for help with military related administrative issues* (Instrumental Support).

2. *...to have complete information on the psychological care of traumatic injuries* (Health Information).

3. *...to have complete information on how to manage my own stress and reactions to what has happened in a healthy manner* (Health Information).

4. *...to have a safe place to process my feelings about my experiences since my family member was injured* (Emotional Support).

5. *...to have a list and description of community-based organizations I can turn to for additional assistance* (Professional Support).

6. *...to feel connected to my home community while I am away caring for my loved one* (Community Support Network).

Additionally, there is no response option for non-applicable items ("N/A"). It might be helpful to have an additional response option on the FNQ-M where family members can indicate that the item was not applicable to them. This will limit confusion between missing items and non-applicable items. Due to a small sample size, I was able to review each FNQ-M with each participant and clarify items that were missing and items that were left blank because they were not applicable.

Feasibility of a Family Needs Assessment

One aim of this study was to test the feasibility of conducting a family needs assessment with family members of the Polytrauma Rehabilitation Center in Richmond, Virginia. As previously stated, results from this study suggest the use of the FNQ-M with the additional aforementioned questioned is appropriate for use with PRC family members. Participants provided narrative feedback to the researcher on the FNQ-M and how they were affected by participating in the study. From an observational perspective, there was no consistent pattern for when family members wanted to schedule their time to participate in the study. Some wanted to schedule it during the patient's therapy appointment, but others did not want to miss any of the patient's therapy. Others wanted to run errands while the patient was in therapy session. Some did not want to leave the patient alone and had to coordinate for someone else to be with the patient in their absence. Family members scheduled appointments at their convenience and this seemed to work well. The average time it took family members to complete the FNQ-M was 10 minutes with a range of 5 to 20 minutes. Because I was present in the room while the family members filled out the FNQ-M, participants sometimes wanted to talk about items as they were filling them out or they would ask for clarification. These situations

accounted for many of the longer times it took for participants to fill out the FNQ-M. No session exceeded 90 minutes.

The present study was designed with respect to minimizing burden placed on the participant, given their busy schedules and recent life-changing events. Although participants were not compensated for their participation in the study, I had hoped that any burden participants felt would be balanced by the opportunity to offer information that might help others in the future. This potential benefit to others was mentioned in the consent form (Appendix C). I had no clear idea how the interview would affect participants and remained conservative with the qualitative freedom built into the study. I know that I prefer to talk about my experiences rather than fit them into a Likert -type scale, but I was not sure if the study population would feel the same way. When directly asked about what it was like to participate in the study, participants offered comments that indicated having an opportunity to express and process their experiences benefited them. They talked about how it allowed them scheduled time away from the patient, a distraction away from their routine, time to express and process their experiences, and the opportunity to offer helpful information to others. Without making a causal conclusion, I will note that the group mean BSI-18 scores did consistently drop for all measured domains (See Table 5). The narrative comments about the benefit of talking about their experiences combined with the change in BSI-18 scores, suggest the participants did benefit from participating in the present study. The reduction in the group mean T-score may also be explained by the fact the participant may feel more comfortable with the researcher and setting during the second session. It also might be accounted for by

increased time spent on the unit as it relates to the family member's adjustment and adaptation to the new setting.

Experiences prior to arriving on the PRC (Phase I)

Participants were asked about their experiences prior to arriving at the PRC in Richmond, Virginia. This information was solicited from participants to educate PRC staff on what family members experience prior to arriving at the PRC. The intent of gathering feedback from participants on what their experiences were like prior to arriving at the PRC had more to with better understanding what experiences family members were bringing with them to the PRC rather than evaluating the program of care at WRAMC and NNMC. Retrospectively, participants provided a wide range of information pertaining to their experiences, but for the most part they can be divided into positive and negative experiences. With respect to the given circumstances of having a family member sustain a severe injury, a positive experience indicates that a family member was satisfied with how their situation was handled. A negative experience indicates that a family member was dissatisfied with how their situation was handled.

Four of the participants reported having a positive experience and six reported having a negative experience. Of the four who reported having a positive experience, one received medical treatment in a non-military hospital for a non-battle injury (NBI). All who reported having positive experiences noted that they were pleased with the medical care the patient received. One participant who reported being please overall with how the military medical community handled her husband's situation, commented that the early communication of medical information was vague and/or inaccurate and that she felt the military medical community was withholding information from her.

Several family members who were dissatisfied with their experiences prior to arriving at the PRC also talked about problems with communication. In addition to talking about communication, dissatisfied participants perceived a lack of availability of staff, lack of TBI knowledge and training among staff, and they commented that they had problems with understanding and navigating the large teams of professionals required to treat a severe injury. They also noted the fact that WRAMC and NNMC are teaching facilities and found this environment distressing and confusing at times. Only one participant commented on the physical condition of the hospital; her interview took place prior to the media's report on the physical conditions of Building 18. There is also narrative data that suggest study participants have the perception that the Navy and the Marines do a better job of taking care of families. Overall, experiences vary greatly from person to person. Much of this can be explained by the contextual model of family stress (Figure 2; Boss, 2006, p.2). The specific nature of the injury, resources, perceptions, and degree of stress and trauma vary by family and change over time differently for families. Family members describe interactions with individual medical professionals, support personnel, different hospitals, and units on different hospitals that all seem to vary. Narrative information from the present study, supported by the contextual model of family stress, suggests the use of individual family needs assessments and subsequent individual programs of care are most appropriate for family members when they arrive on the PRC.

Daily experiences of family members of patients on the PRC (Phase II)

Participants were asked about their experiences after arriving on the PRC. This section will discuss participants' daily experiences while on the PRC, their expectations

for their time on the PRC, opinions on the current program of care, stress and stress management, problems and problem solving, and the impact the injury had on their family at the time of the interview.

Daily experiences. All family members involved in this study were actively involved in the rehabilitation of the injured service member, spending much of their day on the unit. They frequently attended therapies and participated in the care of patient. In addition to being an active member of the treatment team, participants spent time managing their home from a distance (or packing up their home and moving to it to another a state from a distance). Additional experiences varied by individual depending on individual circumstances of the participant. Family members who were not part of the present study population also appeared to be very involved in the rehabilitation of the injured service member. Patients who had a mild brain injury were typically not accompanied by a family member.

Family member expectations of the PRC. Participants were asked what they expected to get out of their experience at the PRC. Overall, family members expected to gain functional outcomes for the patient and education and training for themselves while on the PRC. The level of functional outcome expected varied depending on the patient's current level of functioning and anticipated prognosis. Family members also reported an expectation to receive education and training on how to best assist the patient with his recovery. Family members offered functional outcomes and education and training for themselves as the first response when asked about their expectations. Family members were encouraged by staff to take an active role in the patient's care when appropriate and

the present study suggests that overwhelmingly family members felt involved with the patients care.

Opinions of the program of care on the PRC. Opinions about the program of care on the PRC were collected qualitatively and quantitatively. The quantitative data will be discussed first, followed by the qualitative comments. The FNQ-M provides information pertaining to the program of care. With the exception of *Emotional Support and Instrumental Support* needs, the percentage of needs met exceeded the percentage of needs partially met and not met combined for each domain. *Involvement with Care* needs were most often rated as met (95.5%) followed by *Health Information* (88.3%), *Community Support Network* (67.6%), *Military Support* (63.6%), *Professional Support* (58.2%), *Instrumental Support* (40.9%), and *Emotional Support* (40.9%). The PRC has no control over the military support that it receives from the Office of Seamless Transition (the office that assigns the military liaison to the PRC). The domains most controlled by the PRC staff are health information, involvement with care and professional support items. Most of the instrumental, military, and emotional support items on the FNQ-M are outside of what the PRC staff can directly influence.

According to the narrative data, family members overwhelmingly reported that they were very satisfied with the program of care on the PRC. It is very clear that family members felt the staff and medical director on the PRC worked together to provide sufficient amounts of honest health information in a way the family members can understand. Family members also repeatedly noted that the staff worked and communicated well together. They made many personal comments about the individualized and excellent care they received from the medical director.

During my time on the PRC, I observed former patients and their family members returning to the PRC to visit staff. I feel this is the most telling evidence that suggests families, in general, are very satisfied with the program of care on the PRC. Some former patients chose to have their follow-up care in Richmond, if possible and one relocated to the Richmond area to continue to receive care at the Richmond VA Medical Center. I was initially surprised to hear staff asking returning patients about details that made me think they knew the patient and family under a different context.

Stress management among participants. Participants reported managing their stress with a range and combination of techniques that included distraction, catharsis, seeking emotional support from others, self-care, and smoking. One participant reported taking anti-anxiety medication to manage her stress. Participants were not directly asked about their faith, but throughout the interview two participants referenced using their religious faith to manage their stress and cope with stressful situations. Elements of resilience emerged throughout the interviews. According to its most basic definition, resilience is the ability to absorb stress without breaking (Boss, 2002). Participants in this study, at this phase in the rehabilitation process, appeared to be functioning without evidence of significant health consequences. All participants who smoked, smoked prior to the accident. There was evidence that suggests those who did smoke increased their smoking as a result of the event and the subsequent stress associated with it.

Participants appeared to be adaptively managing the stress and stressful situations associated with their family member's injury. This may in part be due to the PRC staff. To best support today's military families, Watson and Boss (2006) recommend building upon and not ignoring diverse coping strategies that families use. Two particularly

interesting cases I observed that demonstrate how the PRC team built upon family member strengths both involved fathers of younger service members who were in a serious motor vehicle accent. One father was enrolled in the study (Participant #3); the other father declined to be in the study, but chose to share information with me "off line." Because I spent so much time on the unit, I had the opportunity to observe each of these fathers and observe the treatment team's response to these fathers. Both fathers had prior military experience, each retiring from leadership positions. Both fathers (whose time on the PRC did not overlap) verbalized that they were treating their son's rehabilitation as a military mission and put on a (former) military hat to do so. One father related the unknowns of brain injury sequelae to unknowns that typically surround a military deployment or mission. He talked about his son's various treatment goals being mission-training objectives. He viewed his son's daily therapy schedule as a military training schedule. As with military training schedules that are typically "locked-in" 6 weeks out, any changes to his son's daily training/therapy schedule needed (his) prior approval with a full explanation. At times they reported having to mention the fact that they had to "throw around" their rank to make anything happen with the military side of things. One reported feeling discounted as a civilian as he tried to process paperwork with his son's military unit. As with all family members, these fathers were a welcomed member of the treatment team, but unlike typical family members who are grateful to be a member of the team, these fathers were inclined to want to take charge of the team. One father typically arrived before day-shift nurses to learn about changes in his son's condition so that he could "check" day shift nurses. Checking teammates and disseminating information is something instilled in military leaders, but might be poorly received by a

medical staff from a non-medical team member. The PRC staff worked amazingly to meet these two fathers where they were in their crisis. The fathers were functioning and generalizing skills learned in another context to do so. These fathers were navigating a new and uncertain situation in a less than typical manner and the staff impressively accommodated these fathers while maintaining healthy boundaries for themselves. These fathers were demonstrating resilience in the true sense of the word and the staff recognized and supported this. This is one example of how the PRC works to meet family members where they are. The staff flexed to meet the family member rather than the family member always being required to adapt to the environment or system.

The military is not an organization known for flexing to meet service member and their families (or VA employees) where they are; most often it is everyone else who conforms to the military. Boss (2002) underscores this point as she discusses using caution when promoting flexibility and adaptability in certain populations. She notes that in some cases it might be better for certain individuals or groups to stand their ground and not flex, causing crisis and instability in the family or organization. This was recognized by one mother (Participant #9) when she said, "Well, what do we do all the time? We deal with change. My whole life has changed, so adapt." Several participants discussed how they refused to accept what was being offered to them, they remained inflexible and unwilling to bend with what the military was offering them. As result of being asked to bend too much, these participants spoke out and either contacted a congressman or individuals further up the military chain of command. After family members caused this instability for the military, family members reported that efforts were made to accommodate them.

Problems and problem solving among participants. Participants in this study reported few problems they felt they are unable to solve either alone or with the help of the team at the PRC. Some of the problems they reported working through included military administrative issues, legal issues, managing and understanding the various helping resources available to them, and issues that they felt they will have in the future. It is well-documented that family members, specifically primary caregivers of persons with traumatic brain injury (TBI), have long-term needs that change over time and can potentially exhaust their internal resources, subsequently causing negative mental and physical health outcomes (Brooks et al., 1986; Carnes & Quinn, 2005; Lezak, 1986; Mauss-Clum &Ryan, 1981; Perelesz et al., 1999; Rosenbaum & Najenson, 1976). Wade and colleagues (2006) also note that following a brain injury, caregivers need specialized skills in addition to generic problem-solving skills. Although family members appear to have adequate problem-solving skills for what is required of them during the patient's time on an inpatient rehabilitation unit, it might be helpful to assess family member problem-solving skills as they specifically relate to solving-problems related to the brain injury and subsequent behavioral challenges that may arise in the outpatient setting.

Impact of the injury on family members. Participants responded to how the injury had affected their family in a variety of ways. Most participants reported elements of growth as a result of the injury. These elements included gaining an altered perspective of the life and becoming closer to family members. These elements of growth are threaded with loss and include loss of a certain and clearly defined future with in the military. The two dependent military wives enrolled in the study both expressed concerns for their future as it related to their husband's ability to continue to serve on

active duty. Participants talked about how the injury affected their children and siblings of the injured person. Several participants also discussed how the injury affected non-traditional families. Divorced, blended and unblended families face additional challenges in trying to come together to support the family. This boundary ambiguity (not knowing who is in out of the family), as described by Boss (2006) may intensify the stress that surrounds a family as they manage post-injury. Working with non-traditional (and traditional) families requires the staff on the PRC to be flexible and attentive to family dynamics and boundary ambiguity. For example, a mother and spouse of a patient did not want to be on the unit at the same time due to irreconcilable differences; both were seeking guardianship of the patient. The staff worked with both parties to negotiate a schedule that allowed both mother and spouse to be involved in the patient's care. The staff worked to clarify and define the roles of the mother and spouse, specifically when it came to making medical decisions for the patient.

Strengths and Limitations of the Study

The principal strength of this study is that it is the only one of its kind being conducted with family members of patients being treated on a Department of Defense Polytrauma Rehabilitation Center (PRC). The funding it received sent a message to family members and health care professionals that the Department of Veterans Affairs is interested in learning more about military family needs following a polytrauma. It also provides the military and the VA a body of information, gathered by established quantitative measures and supplemented by narrative data, to better understanding of the needs of family members who are present on the PRC and how they react to different environments of care.

A second strength is the use of a mixed-method design that allowed for emic variables to emerge. The terms *etic* and *emic* are frequently used in the multicultural counseling field; etic refers to "universal laws and behaviors that transcend nations and cultures and apply to all human" and emic refers to "constructs or behaviors that are unique to an individual, sociocultural context that are not generalizable" (Ponterotto, 2005, p. 128). Several emic variables (addressed later) specific to military family needs following a polytrauma emerged from this study and merit further investigation in future studies. The identification of these unique variables allows program developers to build upon the existing body of literature pertaining to family member needs following a polytruma while addressing emic needs that extend beyond the established domains of family care.

A third strength of the present study is that it assesses the feasibility of using the FNQ with an inpatient population. Most studies that have used the FNQ to assess family members needs have used an outpatient population (Kreutzer el al., 1994; Kolakowsky-Hayner et al., 2001; Serio et al., 1995). Evidence from the present study suggests that the FNQ-M is suitable for use with an inpatient population, is minimally burdensome, and may provide relief to family members.

Both a strength and a limitation was the role of the researcher. I attempted to be myself as much as possible while spending time on the PRC. I was open about my experiences in Iraq when I felt it was appropriate and I was continually open about my role as an investigator of family needs. I felt like a staff member as well as an onlooker, making both overt and covert observations of the environment and program of care. I wavered between feeling like an insider and an outsider among the staff and the study

participants. I felt as if the staff treated me as a fellow employee, openly sharing with me their frustrations and joys. I never felt as if people were changing their words or actions as a result of my presence. I feel I gained an unobstructed view of the environment, staff members, and patients on the PRC.

A disclosed identity as a former service member and the fact that I shared an office with the medical resident may have hindered my ability to appear neutral. I realize that because of this and general elements of social desirability, participants might not have shared their true opinions with me. I also feel that this is balanced by the very fact that those variables have allowed me to gain unique access to the population and connect in certain ways with participants that might not have been possible otherwise. For example, I am very aware of the emic variable of a perceived constraint within the military to speak out against the military, military medical community, or administration. I addressed this variable as I felt it was appropriate when I felt it surfaced. I also grew to enjoy my work environment over the course of this study and established relationships with and admiration for various staff members. I also used the VA for my personal health care needs and feel my identity as a customer of the VA helped to balance may identity as a staff member.

A second limitation is the small sample size of the present study. A larger sample size would have increased the amount of qualitative data available for analysis. Very little thematic data saturation occurred in this study. Increasing the sample size to 18-20 might have addressed this issue. A larger sample size might have also potentially increased the diversity of this study (by ethnicity and relationship to the patient), another significant limitation. A larger sample size might have also allowed the grouping of

wives, husband, mothers, and fathers into separate categories for analysis, as previous studies suggest that the impact of a brain injury will vary depending on one's relationship to the patient (Mauss-Clum & Ryan, 1981; Perelez et al., 1999; Rosenbaum & Najenson, 1976). Given the pilot nature of this study, however, I feel this limitation is not detrimental to gaining meaningful and useful information from this study.

A third limitation of this study is the cross-sectional design and the variation between participants in time spent on the unit and time since the injury. A longitudinal design that examined family needs at various time points would provide information pertaining to how family needs change over time within a particular phase of treatment and between phases.

Implications and Future Directions

The present study provides insight into the lived experiences of one of several phases of experiences that families and patient are expected to face following a polytrauma. The present study also provided narrative retrospective data on what family members experience prior to arriving on the PRC. Information from this study provide the impetus for the development and evaluation of a large-scale, longitudinal, multi-site individualized family needs assessment program and the simultaneous development of interventions to address the changing needs of caregivers of service members and veterans being treated on the Polytrauma Rehabilitation Center. The use of the FNQ-M will allow clinicians to systematically capture family member needs according to the level of importance those needs carry for the family at the time. Clinicians and team therapists can then efficiently work with family members to address their needs.

Repeated assessment over time will ensure that needs are monitored and addressed as they change over time.

The present study is only a small picture of the wide span of experiences and needs of family members who bear the responsibility of caring for injured service members and veterans. While on the PRC, family members appear to be well-supported and experiencing minimal negative physical and mental health outcomes. However, established research on long-term family needs suggest that family needs change over time. Kolakowsky-Hayner (2001) identified a decline in family members' quality of life after injury relative to pre-injury satisfaction (Brooks et al., 1986; Carnes & Quinn, 2005; Lezak, 1987, 1988; Livingston, 1989, Verhaeghe et al., 2005). Future programming and research should involve as many stages of family member experiences as possible. At a minimum there should be a standardized and consistent program of assessment and care that will follow family member from inpatient to outpatient settings. Family members can then be monitored and assisted as needed during different phases and transitions between phases. Polytrauma patients who are medically discharged from the military and their families will not only face adjustment to life with a disability, but adjustment to life outside the military community. This may impose an additional emic stress on outpatient families and patients.

Family Care Pathway Proposal. To enhance the existing program of care for family members on the PRC, it is proposed that a "family care pathway" be developed for each patient's family member who is actively involved in the patient's care. The family care pathway will function similar to the patient treatment plan that is developed by the treatment team and used to monitor each patient's individual progress through the use of

weekly team goals. It is recommended that a standardized core family care pathway with established time-phase goals and tasks be developed to guide the program of care for family members; this may benefit both staff and family members. It is recommended that the FNQ-M (with the adapted and additional questions) be the assessment tool used to identify each family member's needs and further tailor the core family care pathway to meet individual family needs as they are identified. The use of an adaptable standardized core pathway of care is recommended for several reasons. First, the family care pathway will serve as a way to monitor, track and evaluate the continuum of care family members receive throughout the VA system (from inpatient rehabilitation to community-based outpatient clinic CBOC). Second, the use of an adaptable core family care pathway will promote a seamless transition and continuity of care between treatment facilities for family members. It is recommended that military treatment facilities use this same program of care for families and initiate it as soon as possible after this injury. Third, it is recommended that a master database be established to capture the information from the family care pathway as it changes over time. This information could potential make a significant contribution to the brain injury family caregiver body of literature. It is also recommended that this core family care pathway be implemented and managed by a family health educator who is focused on family member care and is not directly involved in the patient's care. The family health educator would be specially trained in brain injury, military and veteran benefits, and helping skills.

This specialized type of service is currently being provided to families of individuals who are killed in Iraq and the same service should be extended to family members of individuals who are injured and survive, especially given the fact that family

members end up responsible for the long-term care of the injured service member. If a service member is injured in Iraq and subsequently dies, a uniformed service member (casualty assistance officer; CAO) reports to the home of the next of kin and personally notifies the family of the death of the service member. The CAO stays with the family, handling all matters pertaining to the service member, until all matters are settled or until the family releases the CAO. If a service member is injured in Iraq and subsequently lives, this service is not provided. Family members from the present study report that they feel the family health educator positions would best be filled by a person who has been through what they have been through. Grounded in social comparison theory, the idea of a *similar other* (Thoits, Hohmann, Harvey, & Fletcher, 2000) suggests support can best be provided by "a person who has successfully faced a similar situation and can use this experience to establish an empathic relationship that matches the recipient's emotional and practical needs as well as provide credible hope for the future" (Veith, Sherman, Pellino, & Yasui, 2006, p.289). Efforts should be made to recruit similar others, however, it is not realistic to limit the pool of applicants to similar others. Caregivers are busy caring for their family members and it is not realistic to expect that they should be the only individuals considered for such a position. To address this issue, family health educators will ideally have marriage, family, and child counseling, but at a minimum will be trained in helping skills, brain injury rehabilitation, and veteran and military benefits. This training will ensure that family health educators have the skills needed to meet the recipient's emotional and practical needs. Inclusion of outpatient family support groups or "buddy system" is recommended to connect family members

with others who present similar circumstances. This will address community support network needs.

This proposal was modeled after a critical pathway family intervention that was designed by Marks and Daggett (2006) to help nurses identify family needs during the acute and post-acute phases of TBI. The pathway was designed to provide a structured approach to applying nursing interventions to address family needs. This intervention model was designed to address the six aspects of family care addressed by the FNQ (Kreutzer, 1988). For each phase of care there are tasks indicated for each domain of family care. One or more treatment team members are assigned to each task, responsible for completing the task with the family. For example, some tasks may be specific to nursing, social work, or the medical director; other more general tasks are assigned to all treatment team members. Results of the Marks and Daggett (2006) study suggest that staff benefited from this program as well as family members; staff reported they were educated by the pathway tasks as well. Additionally, they recommend the appointment of a family educator to coordinate the administration of the critical pathway program of care for family members (Marks & Daggett, 2006).

It is recommended that the core family care program for polytrauma families include a variety interventions. The present study suggests that family members could benefit from a more structured stress management program and networking family members together who have similar situations. Therapeutic interventions, if needed, can be incorporated into the core family care plan and implemented by a family health educator specifically trained in adjustment and adaptation to caring for persons with severe injuries. Boss (2006) recommends the following therapeutic interventions for use

with individuals who experience an ambiguous loss: naming the problem, dialectical thinking, religion and spirituality, forgiveness, small good works, rituals, positive attribution, sacrifice for a greater good, perceiving suffering as inevitable, and hope. I have observed different family members on the PRC independently practicing these interventions. Naming the situation as ambiguous or unknown appears to work with this population. Several family members reported that they understood that there were many unknowns surrounding the prognosis of the injury and their future in the military. Some demonstrated comfort with the unknown and are moving forward despite the unknown. The medical director, Dr. [medical director], does an excellent job of communicating the ambiguous nature of brain injury to the patient and primary caregiver. He and other staff members acknowledge the ambiguity, but also actively work toward positive outcomes for the patient (modeling dialectical thinking).

Dialectical thinking is the holding of two opposing forces at once. For example, one mother struggled with the idea that her son's body was completely intact, but he remained minimally conscious. She talked about trying to make sense of this as she saw other patients on the unit who were missing arms, legs, and sections of internal organs. She struggled with the fact that her son was "whole" but was not able to respond or move his body purposefully. This same mother also practiced rituals with her son and stayed very involved with his daily care. She would put t-shirts and cologne on him and tried to do the things for him that she felt he would be doing for himself. She also would play music and chant with her son.

Several participants talked about how participating in the study allowed them to potentially help prevent other families from going through the struggles they went

through in the early days following the injury. Small good works may serve as a way a family member can find positive meaning in what happened, but finding positive meaning is a process that takes time (Boss, 2006). A bilingual Latina mother frequently translated information for other Latino families, and all appeared to be providing social support to each other in their native language. This could represent a small good work for this mother, possibly helping her find some meaning her situation. Interventions with families can highlight and reinforce these seemingly small, but very powerful pathways to finding meaning. Again it is important to highlight that interventions with families should be individualized, but guided by a strength-based and skill-based model to promoted active coping and resilience.

In sum, the present study provides a foundation upon which to initiate and build an empirically supported intervention program for families of service members and veterans who are enrolled in the rapidly growing network of polytrauma services within the Veterans Health Administration. The Department of Defense and Department of Veterans Affairs relies heavily on family members for the short and long-term care needs of injured service members and veterans. Continued efforts to improve caregiver quality of life and meet their changing needs will ultimately reduce the strain on VA and DoD resources and positively impact the well-being and health of military service members and veterans with disabilities and their caregivers.

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Table 1

Glasgow Coma Score

Eye Opening (E)	Verbal Response (V)	Motor Responses (M)
4 = Spontaneous 3 = To voice 2 = To pain 1 = None	5 = Normal conversation 4 = Disoriented conversation 3 = Words, but not coherent 2 = No words…only sounds	6=Normal 5=Localizes to pain 4=Withdraws to pain 3=Decorticate posture
		Total = E+V+M

(Teasdate & Jennett, 1974)

Table 2

Rancho Los Amigos Cognitive Scale

I	No Response: Unresponsive to any stimulus.
II	Generalized Response: Limited, inconsistent, nonpurposeful responses, often to pain only.
III	Localized Response: Purposeful responses; may follow simple commands; may focus on presented object.
IV	Confused, Agitated: Heightened state of activity; confusion, disorientation; aggressive behavior; unable to do self-care; unaware of present events; agitation appears related to internal confusion.
V	Confused, Inappropriate: Nonagitated; appears alert; responds to commands; distractible; does not concentrate on task; agitated responses to external stimuli; verbally inappropriate; does not learn new information.
VI	Confused, Appropriate: Good directed behavior, needs cueing; can relearn old skills as activities of daily living (ADLs); serious memory problems; some awareness of self and others.
VII	Automatic, Appropriate: Appears appropriate, oriented; frequently robot-like in daily routine; minimal or absent confusion; shallow recall; increased awareness of self, interaction in environment; lacks insight into condition; decreased judgment and problem solving; lacks realistic planning for future.
VIII	Purposeful, Appropriate: Alert, oriented; recalls and integrates past events; learns new activities and can continue without supervision; independent in home and living skills; capable of driving; defects in stress tolerance, judgment, abstract reasoning persist; may function at reduced levels in society

(Hagen et al, 1972)

Table 3

Sample Size, Education, and Estimated Household Income Means and Standard Deviations; Mean Age = 46.8 years

Variable	Total N (%)	Education Level *M(SD)*	Estimated Household Income *M(SD)*
Gender			
Females	8 (72.7)	14.1 (1.7)	44,750 (18,172)
Males	3 (27.3)	12.0 (2.0)	50,600 (31,829)
Relationship			
Mother	6 (54.5)	14.0 (1.8)	43,833 (21,349)
Wife	2 (18.2)	14.5 (2.1)	47,500 (3,536)
Father	3 (27.3)	12.0 (2.0)	50,600 (31,829)
Husband	0 (00)	NA	NA
Ethnicity			
AA/Black	1 (9.1)	16.0 (0.0)	58,000 (0)
Hisp/Latino	1 (9.1)	14.0 (0.0)	45,000 (0)
EA/White	9 (81.8)	13.2 (2.0)	45,200 (23,084)

Table 4

Family Needs While Assigned to Polytrauma Rehabilitation Center, Richmond, VA – Family Needs Questionnaire – Military (FNQ-M); n = 11

Variable	Mean Level of Importance	*% Need Met*
Health Information	3.9	88.3 %
Emotional Support	2.8	40.9%
Instrumental Support	3.0	40.9%
Professional Support	3.9	58.2%
Involvement With Care	3.5	95.5%
Military Support	3.9	63.6%

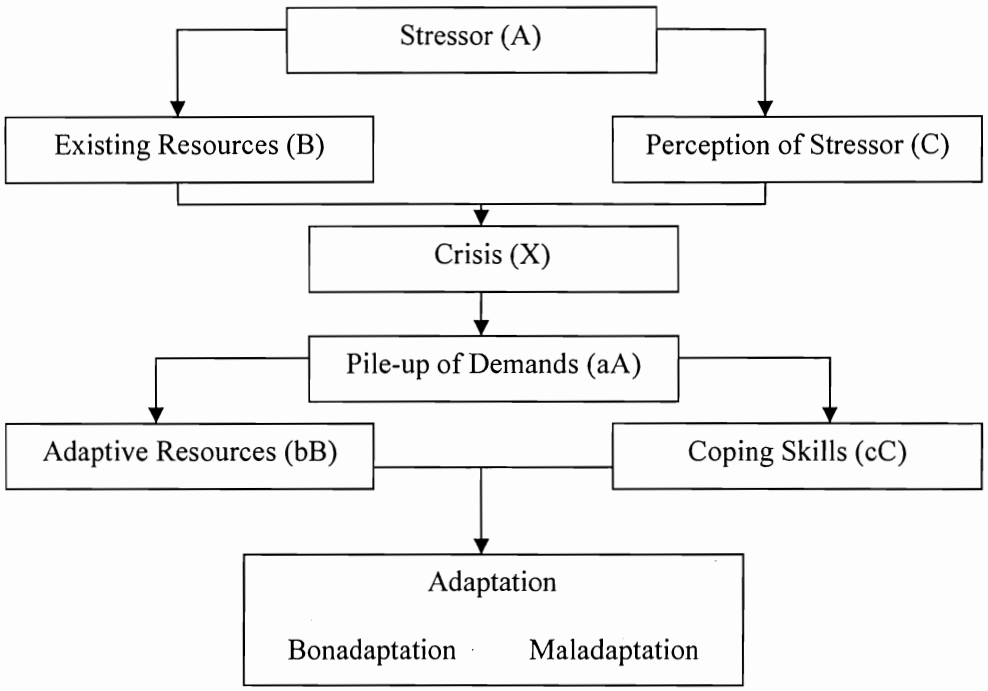
Table 5

Family Member Level of Emotional Distress - Brief Symptom Inventory – 18 (BSI – 18): Pre-Interview and Post-Interview

Variable	Pre-Interview *M (SD)*	Post-Interview *M (SD)*	Change-score *M*
Depression	48.2 (6.8)	45.5 (6.1)	- 3.2
Anxiety	50.8 (10.4)	44.8 (10.3)	- 6.0
Somatization	49.2 (9.3)	46.3 (9.2)	- 3.0
Global Severity Index (GSI)	48.8 (8.7)	44.8 (9.3)	- 4.0

Figure 1

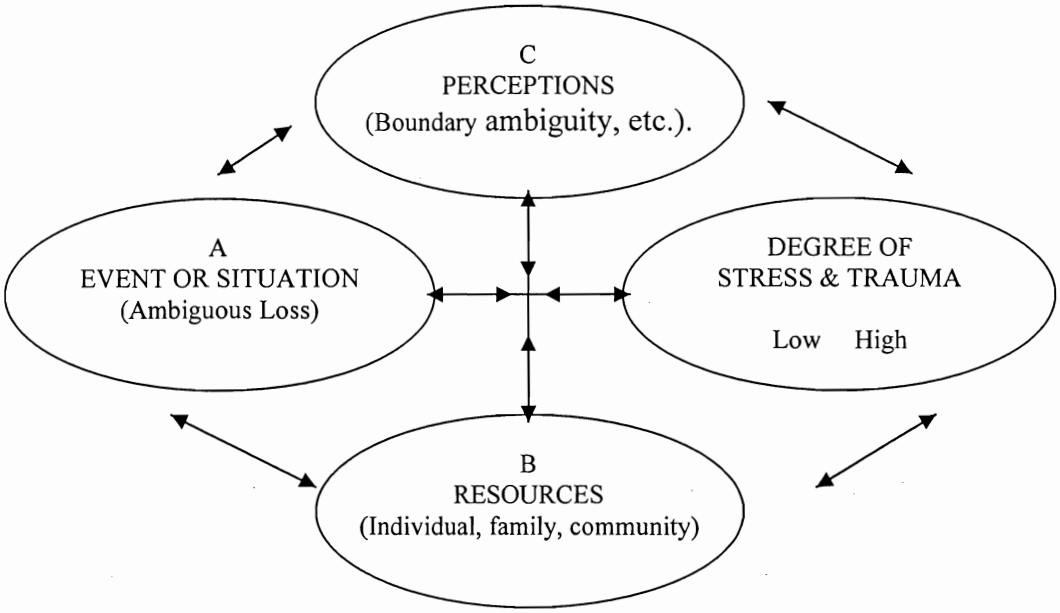
Double ABCX



(McCubbin & Patterson, 1983)

Figure 2

Family Stress Model with Ambiguous Loss and Boundary Ambiguity



(Boss, 2006, p. 12)

Appendix A: Brief Information Sheet

This script will be used by the Polytrauma Rehabilitation Center (PRC) psychologist to inform potential program participants who are appropriate and competent to consent about the *Polytrauma Family Needs Assessment Program.*

"There is a VCU psychology doctoral student, Lisa Harmon, who is a former service member conducting a research study to evaluate the needs of families of service members who have a serious injury. Lisa is interested in learning about the needs of families of injured service members. Lisa is willing to meet with you if you are interested in learning more about the study. Once you talk to her, you can decide if you want to participate in the study. By agreeing to speak with her, you have not agreed to participate in the study, and you can decide that you do not want to at any time. Whether or not you participate in the study does not have any effect on you or your family member's established rehabilitation treatment plan.

Are you interested in talking to Lisa to learn more about the program?"

If [yes] "I will pass along your name and number to Lisa then, I know she'll look forward to speaking with you. Feel free to ask her any questions that you may think of between now and then."

If [no] "Ok, no problem.

Appendix B: Verbal Recruitment Sheet

"Hello, my name is Lisa, and I would like to say THANK YOU to you and your family for your service. All of your personal sacrifices are deeply appreciated by me and every one of the staff members here at the Richmond VA Polytrauma Rehabilitation Center (PRC). [Dr. Benedict or Dr. Pickett] told me that you are interested in learning more about the research study *Polytrauma Family Needs Assessment Program.*

I am a doctoral student from VCU, a local university affiliated with Hunter Holmes McGuire VAMC in Richmond, Virginia. I am also a former service member and served in Iraq in 2004. I am interested in learning more about how you and your family are coping with your family member's injury and the rehabilitation process. Many families who have a family member with a serious injury have similar needs, but many families have unique needs that continue to go unmet. Participating in the *Polytrauma Family Needs Assessment Program* will allow you to identify your met and unmet needs to help us better understand what life has been like for you since you were notified that your family member was injured. Although we cannot guarantee that your participation will help us meet your needs, this information may be used in the future to better address the needs of families in similar situations.

This research study involves participating in two 30-90 minutes sessions consisting of filling out some questionnaires and answering interview questions. Both sessions will take place during the time that your family member is receiving treatment at the McGuire Polytrauma Rehabilitation Center (PRC) in Richmond, Virginia. Participation in this study is completely voluntary. If you choose to participate in the study, you may withdraw from the study at any time. You and your family member will not be penalized if you chose to withdraw from the study; if you choose to remain in the study, you may choose which questions you want to answer.

The interview will be audio taped and all items pertaining to this study will be kept in a locked cabinet. All information collected during the program will be kept confidential and anonymous. That means your name will not be associated with the information you provide to us. I can further explain how we will protect your information if you are interested in participating in the study."

"Are you interested in participating?"
[If no]: "Ok, that is not a problem. Thank you for meeting with me. I wish the best to you and your family during [service member's name] rehabilitation. If at any time you change your mind, please feel free to contact Dr. Benedict, Dr. Pickett, or me."
[If yes]: "Great. I would first like to review the informed consent form (IFC) with you because it gives a detailed account of what the study involves. Remember, at anytime you can say that you are not interested in participating and you and your family member will not be penalized in any way for not participating."
[Review ICF with potential participant and note that the potential participant may keep the unsigned ICF to review it further with family and friends.]
Do you have any questions?"
[If no]: Obtain informed consent and schedule two sessions with the participant.
[If yes]: Answer questions.
"Are you still interested in participating?"
[If yes]: Obtain consent and schedule two sessions with the participant.
"Thank you very much for your time. I look forward to talking to you."

Appendix C: Informed Consent

Department of Veterans Affairs

VA RESEARCH CONSENT FORM

Subject Name: _____ **Date:**_____

Title of Study: **Polytrauma Family Needs Assessment Program**

Principal Investigator: Lisa Harmon **VAMC: McGuire (Richmond, VAMC)**

This Consent Form Includes Required Elements Of Informed Consent.

Table of Contents:

Title of Research:
Sponsor: N/A
Protocol No: N/A
Investigator name and address:

Title of Research: Polytrauma Family Needs Assessment Program

Protocol No:
Investigator Name and Address: Lisa Harmon
Polytrauma Rehabilitation Center (Unit2B)
1201 Broad Rock Blvd.
McGuire VA Medical Center, Richmond,VA

1. What is this research study about? (Introduction)

You are being asked to be in this research study because you have a family member who has a severe injury. Your participation at all times is entirely voluntary.

The purpose of this study is to better understand the issues that you have had to deal with since you were notified that your family member was injured.

If you agree to be in this study, you will be asked to share some personal information about what your life has been like since your family member was injured. Other information that you will be asked to share include how you are feeling physically and mentally, what types of medications you are taking, what your needs and expectations are and how they have been addressed. This information will be gathered from a questionnaire and an interview. You do not have to answer any questions that you do not want to during any part of either of the sessions. Approximately 30 subjects will participate in this study.

2. What is expected of me? (Procedures)

Participation in this study is voluntary. If you choose to participate, you will be asked to be present for two, 30-90 minute individual sessions with the study team. These sessions will take place at the Polytrauma Rehabilitation Center (PRC), McGuire VAMC (unit 2B) and will be scheduled at your convenience.

Session 1: Approximate length = 30-90 minutes
You will be asked to meet with an investigator who will give you several questionnaires to fill out. If you need assistance in filling out this questionnaire, a member of the research team will be present the entire time to help you with this and to answer questions that you may have.

You will be asked to fill out three questionnaires about your personal information, how you are feeling physically and mentally, what types of medications you are

taking, what your needs are, how important those needs are to you, and if your needs have been met. You will also be asked if you are enrolled in any other studies. These questionnaires will either be fill-in-the blank, or multiple choice. Remember, you do not have to answer any questions that you do not want to answer at any time during this session.

Session 2: Approximate length = 30-90 minutes; Scheduled 2 weeks after Session 1
You will be asked to meet with the investigator and at that time the investigator will begin the tape recorder, say your study identification number, and begin asking you a list of questions. You will be asked to verbally respond to these questions. These questions will ask you about your experiences after you were notified that your family member was injured and you will be able to openly answer these questions with as much or as little information as you would like to share. You will be asked to sign a separate consent form for using the tape recorder.

Following the interview, you will be asked to fill out one of the questionnaires similar to one you filled out in the first session.

You do not have to answer any questions that you do not want to during this session. You and your family member will not be penalized if you chose not to answer any questions or if you wish to discontinue participation altogether.

Upon request, you will be provided with the results of the Polytrauma Family Needs Assessment Program when they become available.

3. Will the research benefit me? (Benefits)

There is no guarantee that you will receive any benefit from participating in this study. This is not a treatment study. This study is designed to collect information about what your life has been like since you were notified that your family member was injured. The information obtained may help other families with a similar situation in the future.

4. What are my alternatives to being a research subject? (Alternative Therapy)
This is not a treatment study. Your alternative is not to participate in this study.

5. What are my risks? (Risks, Inconveniences, Discomforts)
There is minimal risk associated with participating in this study. Talking about your current situation might cause you to become upset, but it might also help you feel better. To minimize your risk of becoming upset, you may skip any questions that you do not want to answer and you may discontinue participating in the study at any time with no penalty to you or your family member.

All information collected from you during this study will be confidential, except if you say that you may cause injury to yourself or others or if you report current physical or sexual abuse. This information must be reported to the proper authorities. Depending on the circumstances, the report may need to be made to the police, child or adult protective services, or school/nursing home personnel.

6. Will I get paid? (Compensation)
You will not be paid for your participation in the *Polytrauma Family Needs Assessment Program*. You will not be paid for any travel or personal expenses that you have while participating in the study. Every effort will be made to schedule your two session appointments around the time that you plan on being at the Polytrauma Rehabilitation Center (PRC).

7. Will I have to pay? (Cost of Participation)
There are no costs associated with participating in this study other than the time you will spend in interviews and filling out questionnaires.

8. Does pregnancy prevent me from participating? (Pregnancy)
Every effort will be made to have females enter this study. Pregnancy does not prevent you from participating in this study.

9. What if I get injured? (Research Related Injury)
In the event of injury while participating in this research study, McGuire Veterans Affairs Medical Center (VAMC) may or may not provide compensation, depending on applicable federal regulations. If injury occurs at the VAMC, medical treatment will be available at the VAMC. By signing this form you have not given up any of the legal rights which you would otherwise have.

10. Are my records safe from the public? (Confidentiality of Records)
You will be assigned a study number so that your name will not be associated with any of the answers that you will give. The only form in this study that will contain your name is this consent form and one master participant list that will have all of the names and numbers of each individual who participates in the study. We expect there will be 30 individuals in this study. This master participant list, all forms, and tapes pertaining to this study will be kept in a manner consistent with the Privacy Rules, meaning it will be locked in a file cabinet in a locked room. Only the Principal Investigator and sub-investigator will have access to the list. A copy of the Privacy Rules may be provided to you upon request.

11. Do I have to participate in this study or can I withdraw from the study? (Voluntary Participation and Withdrawal)
Participation in this study is voluntary and you may refuse to participate without penalty to you or your family member. The Principal Investigator (PI) will answer any questions you may have about the study. Remember, you are free to withdraw your consent and stop participation at any time. Stopping will in no way

change the quality of care you or your family member receives now or in the future at this institution or your right to participate in other studies.

Any significant new findings that develop during the research study that may affect your decision to continue participating will be provided to you as soon as possible.

Your participation in this research study may be ended without your consent for the following reasons:

- If the study staff believes, for any reason, that it is within your best interest.
- McGuire IRB may also end the study at any time.

12. Whom should I contact for emergency questions? (Contacts)

If you have any questions, concerns or complaints regarding this study please call:

Dr. Treven Pickett
Polytrauma Rehabilitation Center
1201 Broad Rock Blvd.
Richmond, Virginia 23224
(804) 675-5000 ext. 2801
treven.pickett@va.gov

Lisa Harmon
Polytrauma Rehabilitation Center
1201 Broad Rock Blvd.
Richmond, Virginia 23224
(804) 828-5794 ext. 2801
harmonal@vcu.edu

If you are unable to reach any of the health care providers listed and need immediate medical assistance for a research related injury please call the VAMC hospital operator at 800-784-8381 and ask for the Emergency Room physician to obtain advice, or call the Emergency Room directly at 800-675-5527. If you have any questions concerning your rights as a research participant, you may contact the McGuire Institutional Review Board (IRB) at 804-675-5676. The IRB is responsible for reviewing research with human subjects and verifying that safety, integrity and human rights of subjects are protected.

13. Date of Consent Form Revision:

June 21, 2006, October 11, 2006

Department of Veterans Affairs

Subject Name: _____ Date:_____

Title of Study: Polytrauma Family Needs Assessment Program

Principal Investigator: Lisa Harmon VAMC: Hunter Holmes McGuire VA Medical Center

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above.

Dr. Pickett (or associate) has explained the study to me and answered all of my questions. I have been told of the risks or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty or loss of VA or other benefits to which I am entitled. The results of this study may be published, but my records will not be revealed unless required by law. I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

_____ _____
Subject's Signature Date/Time

_____ _____
Signature of Subject's Representative * Print Name/Date

_____ _____
Signature of Witness Print Name/Date

_____ _____
Signature of Person Obtaining Informed Consent Print Name/Date

_____ _____
Signature of Investigator Print Name/Date

*Only required if subject is not competent.

VA FORM **10-1086** IF MORE THAN ONE PAGE IS USED EACH PAGE MUST BE CONSECUTIVELY NUMBERED

Appendix D: Demographics Questionnaire

Date:_____

Gender_____

Age_____

Relationship to patient_____

Are you currently participating in **any other** Department of Defense (DoD) or Veterans Administration (VA) research studies? Y or N (please circle one)

If "yes" to participating in any other study, please list the name and any information you have about the
study_____

What is your race? Please check all that apply.

_____American Indian/Alaska Native
_____Asian
_____Native Hawaiian or Other Pacific Islander
_____Black or African American
_____White
_____Hispanic/Latino
_____Other

Estimate household income per year $_____

Your employment status. Please check all that apply.
_____employed
_____unemployed
_____retired
_____volunteer _____other_____ (please list)

Your education level_____

Please list all prescription and over-the-counter medication you are currently taking
_____

_____

_____

Date your family member was injured
(day/month/year):_____

Date you were notified your family member was injured
(day/month/year):_____

Geographic location where the injury occurred
(country):_____

Your geographic location at the time you were notified your family member was injured
(state and/or country):_____

What were you told about your family member's injury when you were initially

notified?_____

_____

_____

Date you first saw your family member after he or she was injured
(day/month/year):_____

Where did you first see your injured family member after the
injury?_____

Please indicate how severe you think the injury is, on a scale of 1 to 5. Please circle a number below.

Not severe Somewhat severe Very severe

1.....2.....3.....4.....5

Is there anything else you would like us to know about you?

_____

_____

_____

Appendix E: Family Needs Questionnaire – Military (FNQ-M)

FAMILY NEEDS QUESTIONNAIRE

Your Name: _____ Date: ____-____-____

INTRODUCTION: *Family and/or friends of persons who have had a traumatic injury often find they have their own special needs. These needs may or may not have been taken care of during the patient's rehabilitation. Often, these needs change over time. We are interested in seeing how important some of these needs are to you and whether or not those needs have been met. The information you provide will help us to understand the needs of your family as well as other families of persons with serious injuries.*

DIRECTIONS: *For each of the following 40 questions please use the scales described below to tell us about your needs. Each question contains two parts.*

PART I

For each statement, use the scale below to show how important you feel these needs are by placing a circle around the number which best describes your answer. After rating each statement as 1, 2, 3, or 4, use the second scale (right) to relate whether each need is being met.

1	2	3	4
Not Important	Slightly Important	Important	Very Important

PART II

Use the next scale to tell us whether a need has been met. Circle Y (Yes) if the need has been met, circle P (Partly) if the need has only partly been met, and circle N (No) if the need has not been met at all.

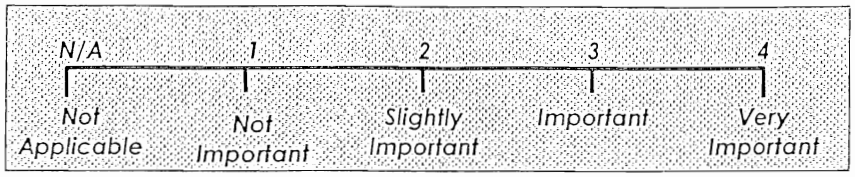
Y	P	N
YES	Partly	No

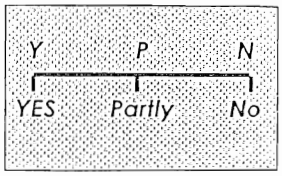
EXAMPLES:

This person rated the need as "Important"

The need was rated as being "Partly Met"

1. I need to get enough rest or sleep | 1 | 2 | (3) | 4 | Y | (P) | N





I NEED	PART I *How Important is this need?*				PART II *Has this need been met?*		
1. to be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	1	2	3	4	Y	P	N
2. to be told daily what is being done with or for the patient.	1	2	3	4	Y	P	N
3. to give my opinions daily to others involved in the patient's care, rehabilitation, or education.	1	2	3	4	Y	P	N
4. to be told about all changes in the patient's medical status.	1	2	3	4	Y	P	N
5. to be assured that the best possible medical care is being given to the patient.	1	2	3	4	Y	P	N
6. to have explanations from professionals given in terms I can understand.	1	2	3	4	Y	P	N
7. to have my questions answered honestly.	1	2	3	4	Y	P	N
8. to be shown that my opinions are used in planning the patient's treatment, rehabilitation or education	1	2	3	4	Y	P	N
9. to have a professional to turn to for advice or services when the patient needs help	1	2	3	4	Y	P	N
10. to have different professionals agree on the best way to help the patient.	1	2	3	4	Y	P	N
11. to have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery).	1	2	3	4	Y	P	N
12. to have complete information on the patient's physical problems (e.g., weakness, headaches, dizziness, problems with vision or walking).	1	2	3	4	Y	P	N

N/A	1	2	3	4
Not Applicable	Not Important	Slightly Important	Important	Very Important

Y	P	N
YES	Partly	No

I NEED	PART I HOW IMPORTANT IS THIS NEED?				PART II HAS THIS NEED BEEN MET?		
13. to have complete information on the patient's problems in thinking (e.g., confusion, memory, or communication).	1	2	3	4	Y	P	N
14. to have complete information on drug or alcohol problems and treatment.	1	2	3	4	Y	P	N
15. to be told why the patient acts different, difficult or strange.	1	2	3	4	Y	P	N
16. to be told how long each of the patient's problems is expected to last.	1	2	3	4	Y	P	N
17. to be shown what to do when the patient is upset or acting strange.	1	2	3	4	Y	P	N
18. to have information on the patient's rehabilitative or educational progress.	1	2	3	4	Y	P	N
19. to have help in deciding how much to let the patient do by himself/herself.	1	2	3	4	Y	P	N
20. to have enough resources for the patient (e.g., rehabilitation programs, physical therapy, counseling, job counseling).	1	2	3	4	Y	P	N
21. to have enough resources for myself or the family (e.g., financial or legal counseling, respite care, counseling, nursing or day care).	1	2	3	4	Y	P	N
22. to have help keeping the house (e.g.., shopping, cleaning, cooking, etc.)	1	2	3	4	Y	P	N
23. to have help from other members of the family in taking care of the patient.	1	2	3	4	Y	P	N
24. to get enough rest or sleep.	1	2	3	4	Y	P	N
25. to get a break from my problems and responsibilities.	1	2	3	4	Y	P	N
26. to spend time with my friends.	1	2	3	4	Y	P	N
27. to pay attention to my own needs, job or interests.	1	2	3	4	Y	P	N

N/A	1	2	3	4
Not Applicable	Not Important	Slightly Important	Important	Very Important

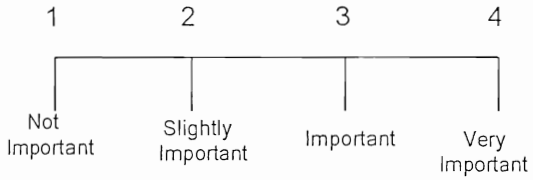
Y	P	N
YES	Partly	No

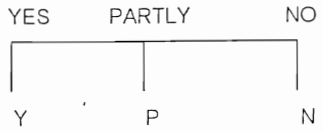
I NEED	PART I *How Important is this need?*				PART II *Has this need been met?*		
28. to be told if I am making the best possible decisions about the patient.	1	2	3	4	Y	P	N
29. to have my significant other understand how difficult it is for me	1	2	3	4	Y	P	N
30. to have my partner or friends understand how difficult it is for me.	1	2	3	4	Y	P	N
31. to have other family members understand the patient's problems.	1	2	3	4	Y	P	N
32. to have the patient's friends understand his/her problems.	1	2	3	4	Y	P	N
33. to have the patient's employer, coworkers or teachers understand his/her problems.	1	2	3	4	Y	P	N
34. to discuss my feelings about the patient with someone who has gone through the same experience.	1	2	3	4	Y	P	N
35. to discuss my feelings about the patient with other friends or family.	1	2	3	4	Y	P	N
36. to be reassured that it is usual to have strong negative feelings about the patient.	1	2	3	4	Y	P	N
37. help getting over my doubts and fears about the future.	1	2	3	4	Y	P	N
38. help in remaining hopeful about the patient's future.	1	2	3	4	Y	P	N
39. help preparing for the worst.	1	2	3	4	Y	P	N
40. to be encouraged to ask others to help out.	1	2	3	4	Y	P	N

If there are other needs that were not included on this questionnaire, please write them below:

Developed by the Rehabilitation Psychology & Neuropsychology Service, Department of Physical Medicine and Rehabilitation, Medical College of Virginia of Virginia Commonwealth University, Richmond. Revised 5/96

Family Needs Questionnaire-Military
Participant identification number_____





I NEED.....	PART I How important is this need?	PART II Has this need been met?
41. to have a military representative to turn to for help with military-related issues.	1 2 3 4	Y P N

Have we missed anything? Please fill in any needs we have not identified, how important they are to you, and if they have been met, partially met or not met.

42. _____	1 2 3 4	Y P N
43. _____	1 2 3 4	Y P N
44. _____	1 2 3 4	Y P N
45. _____	1 2 3 4	Y P N
46. _____	1 2 3 4	Y P N
47. _____	1 2 3 4	Y P N
48. _____	1 2 3 4	Y P N
49. _____	1 2 3 4	Y P N
50. _____	1 2 3 4	Y P N

Appendix F: Brief Symptom Inventory – 18 (BSI-18)

INSTRUCTIONS: The BSI – 18 tests consists of a list of problems people sometimes have. Read each one carefully and circle the number of the response that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem. Do not skip any items. If you change your mind, draw and X through your original answer and then circle your new answer. Read the example before you begin. If you have any questions, please ask them now.

EXAMPLE:

0 = Not at all 1 = A little bit 2 = Moderately 3 = Quite a bit 4 = Extremely

How much were you distressed by:

Body aches..... 0 1 2 (3) 4

0 = Not at all 1 = A little bit 2 = Moderately 3 = Quite a bit 4 = Extremely

How much were you distressed by:

1. Faintness or dizziness..... 0 1 2 3 4
2. Feeling no interest in things..... 0 1 2 3 4
3. Nervousness or shakiness inside..... 0 1 2 3 4
4. Pains in heart or chest..... 0 1 2 3 4
5. Feeling lonely..... 0 1 2 3 4
6. Feeling tense or keyed up..... 0 1 2 3 4
7. Nausea or upset stomach..... 0 1 2 3 4
8. Feeling blue..... 0 1 2 3 4
9. Suddenly scared for no reason..... 0 1 2 3 4
10. Trouble getting your breath..... 0 1 2 3 4
11. Feelings of worthlessness..... 0 1 2 3 4

0 = Not at all 1 = A little bit 2 = Moderately 3 = Quite a bit 4 = Extremely

How much were you distressed by:

12. Spells of terror or panic.....	0	1	2	3	4
13. Numbness or tingling in parts of your body.....	0	1	2	3	4
14. Feeling hopeless about the future.....	0	1	2	3	4
15. Feeling so restless you couldn't sit still.....	0	1	2	3	4
16. Feeling weak in parts of your body.....	0	1	2	3	4
17. Thoughts of ending your life.....	0	1	2	3	4
18. Feeling fearful.....	0	1	2	3	4

Appendix G: Interview Questions

1. *What is your opinion of the surveys that you filled out the last time we met?*

Prompt: The survey that asked you to rate your needs and if they were met, partially met, or unmet.

Prompt: The survey that asked you about how distressed you were in the past 7 days.

Prompt: What are some items that should have been addressed, but were not?

This is an "opinion" question that asks for feedback on the empirically supported questionnaires that the family member will fill out in the first session of the study. This question transitions the family from the first session to the second session. This question will also be used to further establish rapport between the interviewer and the participant. The participant will be able give feedback on the first session and the interviewer will verbally and non-verbally communicate to the participant a deep and genuine interest in the participant's opinion. Patton (2002) emphasizes "the quality of the information obtained during an interview is largely dependent on the interviewer" due in part to genuine interest and part to clinical skills (p. 314).

2. *If I followed you though a typical day of what your life has been like since you were notified that your family member was injured, what would I see you doing?*

Prompt: What experiences would I observe you having?

This is an "experience" question used to gather information on the subjective experience of the family member. This is an important question to ask because medical center staff members only see a snapshot of the family while the family is present on the polytrauma rehabilitation unit. This question also further establishes rapport because it allows the opportunity for the interviewer and interviewee to journey together though a typical day guided by the interviewee.

3. *How has the military medical community has handled your situation?*

Prompt: Pertaining to your family member being injured?

This is an "opinion" question that gives the family member an opportunity to freely express his or her opinion on how the military medical community has handled the injured service member's medical evacuation, stabilization, and transition to rehabilitation. This is important information that may be used to better develop services/programs for family members.

4. *What do you know about your family member's condition, treatment, and prognosis?*

This is a "knowledge" question that will assess how much information the family member knows about the injury. Knowledge about the family member's injury has been reported as one of the most important needs assessed by the Family Needs Questionnaire (FNQ) used in the first session of this study (Kreutzer, et al.,

1994). Answers to this question will provide data on what information family members do know about the condition, treatment, and prognosis of their family member.

5. *Are there problems that you are facing that you do not know how to solve or have been unable to solve?*
Prompt: If so, what are some of those problems?
Prompt: How have you attempted to solve these problems?

This question is a "behavior" question that addresses the skills that family members use to solve problems. Problem-solving is a teachable skill that may be taught to families and then transferred to other life domains. Elliot and colleagues (2001) note problem-solving abilities are "particularly appealing to clinical researchers as evidence indicates that training in social problem-solving abilities has been effective in treating depression and distress, and in improving self-management skills" (p. 224). Again this information may be used as rationale for the development and/or implementation of a new or existing skill-based intervention program for families.

6. *How do you manage your stress?*
Prompt: How helpful has this been?

This question is a "behavior" question that assesses the coping skills family members use to deal with the stress of receiving a severely injured service member home from war. Stress management techniques are skills that may be taught to families and then transferred to other life domains. Aldwin and colleagues (1994) report most studies of stress have demonstrated negative sequelae of stressors. Coping is a complicated construct in how it is defined, measured, and taught. Again this information may be used as rationale for the development and/or implementation of a new or existing skill-based intervention program for families.

7. *How has your family member's injury changed or affected your family?*

This is an "experience" question that will provide the family member with an opportunity to provide meaningful information about changes in communication and roles within the family following a serious injury. Kreutzer and Taylor (2004) recommend addressing effects of a severe injury on the surviving family as part a comprehensive intervention "to satiate the complex needs of families after brain injury" (p.3).

8. *What do you expect to get out of your experience at the polytrauma rehabilitation center (PRC) by the time your family member is discharged?*
Prompt: Are you hopeful these things will happen?

This is an "opinion" question that will provide information about what the family members expect to get out of their experience at the PRC.

9. *What is your opinion about talking with someone about these issues who has served in the military?*

This is an "opinion" question that is derived from personal experience and personal conversations with fellow veterans from Iraq and Viet Nam wars, family members of veteran peers, and staff members from two different Veterans Administration Medical Centers.

10. *Is there anything I haven't asked you that you feel would be helpful/important for me to know?*

This is an "opinion" question that provides the opportunity for the family member to address any unidentified themes he or she feels is important.

11. *What has it been like for you to talk about these issues?*

This is an "experience" question that will serve as a way to gather information on the process of this type of inquiry with this population.

Vita

Anna Lisa Harmon was born on February 25, 1973 in Norman, Oklahoma. She graduated from Shikellamy High School, Sunbury, Pennsylvania, in 1991. She received her Bachelor of Science in Psychology from the United States Military Academy, West Point, New York in 1996. She was commissioned as an officer in the United States Army Quartermaster Corps and served for five years on active duty and four in the reserves, serving one tour of duty in Iraq in 2004. She resigned her commission and received an honorable discharge from the Army in 2005. She completed a Master of Science in Counseling Psychology from Virginia Commonwealth University in 2006.